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A Psychosocial Intervention for Children with Autism Spectrum Disorder in the Outpatient Surgery Unit

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A Psychosocial Intervention for Children with Autism Spectrum Disorder in the Outpatient Surgery Unit

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For my grandmothers, parents, sister, brother, and brother-in-law.

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A Psychosocial Intervention for Children with Autism Spectrum Disorder in the Outpatient Surgery Unit

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Visiting the hospital is stressful for all children, especially for those with autism spectrum disorder (ASD). Characteristics of children with ASD make this population particularly vulnerable to stress in the hospital. Typical psychosocial interventions for hospitalized children are not always effective for children with ASD. The purpose of this study was to test the effectiveness of a psychosocial intervention program aimed at minimizing the stress experienced by and the incidence of challenging behaviors exhibited by patients with ASD, and thereby minimizing the stress of their parents and perioperative nurses who directly care for these patients in the outpatient surgery unit. There were 48 patient participants and 47 parent/legal guardian participants in the comparison and intervention groups. There were 58 perioperative nurses who participated in both the comparison and intervention groups. ANCOVA models were estimated to test the fidelity and effectiveness of the intervention protocol. Ordinary least squares regression analyses were used to test the effectiveness of the intervention program using four moderators. Results from these analyses indicated that the intervention program was effective at lowering the stress levels for (1) parents of children ages 2–5 years old, (2) patients (and the parents of children) with lower levels of challenging behavior reported on a daily basis, (3) patients (and the parents of patients) who were verbal, and (4)

patients ages 6–12 years old. Promising results were found when analyzing the amount of challenging behaviors exhibited by the patients, specifically for the preoperative and post-operative discharge nursing groups. The intervention was also effective at lowering operating room nurses' stress level when caring for patients and their parents who reported lower parenting stress on a daily basis. The successful implementation and evaluation of this pilot study brings the healthcare community one step closer to finding a way to help all children with ASD and their parents, as well as the medical staff who care for them.

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Introduction

Visiting the hospital is stressful for all children. It is a new and potentially frightening environment where children may experience pain, undergo invasive procedures, and be separated from their parents and siblings. To help children cope with their medical experiences, child life specialists provide developmentally appropriate education for medical procedures, encourage emotional expression through play, and empower parents to provide support for their children. However, these typical psychosocial interventions for hospitalized children are not always effective for children with autism spectrum disorder (ASD). Some children with ASD are so distressed upon entering the hospital that they display challenging behavior (e.g., aggression) and are unable to calm themselves enough to play or receive developmentally appropriate education about their upcoming procedures. Oftentimes, parents are even unsure of how to calm their child once his or her behavior has escalated.

Unfortunately, children with ASD visit the hospital more frequently than typically developing children (Venkat, Jauch, Russell, Crist, & Farrell, 2012; Atladóttir, Schendel, Lauritsen, Henriksen, & Parner, 2012; Scarpinato et al., 2010), and thus the challenges posed by caring for patients with ASD are ones felt in healthcare environments throughout the country. Both parents of children with ASD and medical staff who work with these children are aware that healthcare environments can be particularly stressful for children with ASD (Davit, Hundley, Bacic, & Hanson, 2011; Scarpinato et al., 2010), and the stress these children experience is likely to affect the stress levels of their parents and the medical staff caring for the children. Yet, despite the fact that children with ASD are frequent hospital patients and pose potential difficulties for medical staff, there is very little research about or clinical guidance for the psychosocial care of children with ASD in healthcare environments, especially the outpatient surgery unit.

The purpose of this study was to test the effectiveness of a psychosocial intervention program, the Special Needs Assessment and Plan (SNAP) intervention program, aimed at minimizing the stress experienced by patients with ASD and thereby minimizing the stress of their parents and perioperative nurses who directly care for these patients in the outpatient surgery unit. The psychosocial intervention program was developed considering the developmental stressors of children in healthcare environments, and the characteristics and challenges faced by children with ASD. The intervention consisted of (1) an educational seminar about ASD for perioperative nursing staff, (2) the collaborative creation of an individualized coping plan by a child life specialist and the parent of a child with ASD, and (3) the implementation of the child's individualized coping plan.

AUTISM SPECTRUM DISORDER

According to the United States Centers for Disease Control and Prevention, one in 68 children is diagnosed with ASD (Christensen et al., 2016). Autism spectrum disorder is a neurodevelopmental disorder characterized by impairments in social interaction and communication and by restrictive and repetitive behaviors (American Psychiatric Association [APA], 2000; APA, 2013). The Diagnostic and Statistical Manual 4th edition, text revision (DSM-IV-TR) categorized autistic disorder, Asperger's disorder, and pervasive developmental disorder-not otherwise specified (PDD-NOS) under a general category of pervasive developmental disorders (APA, 2000; CDC, 2016). In 2013, the Diagnostic and Statistical Manual 5th edition (DSM-V) removed the autistic disorder, Asperger's disorder, and PDD-NOS diagnoses and developed one broad category that classified all children who exhibit persistent deficits in social communication and social interaction, and restrictive, repetitive patterns of behavior, interests, or activities under the umbrella diagnosis of ASD (APA, 2013). The social

communication and interaction criteria include deficits in social-emotional reciprocity (e.g., back-and-forth conversation), nonverbal communicative behaviors (e.g., understanding body language or gestures), and the development and maintenance of relationships (APA, 2013). The criteria for restrictive, repetitive patterns of behavior include repetitive motor movements (e.g., flipping objects) or use of speech (e.g., echolalia), insistence on sameness or ritualized patterns of behavior (e.g., extreme distress to small change), highly fixated, narrow interests (e.g., wheels), and hyper- or hypo-reactivity to sensory input (e.g., tantrum when he or she hears a loud noise; APA, 2013). Children with ASD are known have difficulty in new environments, transitions from one activity to another, and experiences out of their usual routine (APA, 2013; CDC, 2016; Seid, Sherman, & Seid, 1997) and may also exhibit unusual reactions to what they see, hear, taste, touch, and smell (CDC, 2016; Ben-Sasson et al., 2009; Lang et al., 2012; Danesh & Kaf, 2012). These symptoms can make visiting the hospital a particularly stressful experience. To diagnose ASD in children, physicians must specify the severity of ASD symptoms (i.e., levels 1 to 3, from "requiring support" to "requiring very substantial support") and whether or not the child has accompanying intellectual disability or language impairment (APA, 2013). Both intellectual disability and language impairment are common comorbidities with an ASD diagnosis and are discussed further.

Intellectual Disability

Intellectual disability (ID) is a developmental disability that occurs in 32% to 65% of children with ASD (Christensen et al., 2016; Matson & Shoemaker, 2009; McGonigle-Chalmers & McSweeney, 2013; Bishop, Farmer, & Thurm, 2015). There is range in the prevalence of ASD and ID because it is difficult to diagnose ID if children also have language impairment (Bauman, 2010; Jang & Matson, 2015). Intellectual disability is defined by significant impairment in intellectual functioning and adaptive behaviors

before the age of 18 (American Association on Intellectual and Developmental Disabilities [AAIDD], 2013). Intellectual functioning involves learning, reasoning, and problem solving skills, and adaptive behavior involves practical, conceptual, and social skills (AAIDD, 2013). Practical skills include daily living skills (i.e., bathing), use of money, caring for one's health, and use of the telephone; conceptual skills include language, reading, writing, and number concepts; and social skills include self-esteem, social problem solving, and avoidance of being victimized (Tassé et al., 2012). Deficits in adaptive behavior can make daily living more difficult for children with ID and, as a result, make daily living more difficult for their parents, teachers, and other caregivers. Children with ID may not understand why they need to visit a doctor or have a medical procedure, and might require more assistance when they receive medical treatment in a hospital setting compared to their typically developing peers.

Language Impairment

Kanner (1943), the first physician to report on children with ASD, described delayed and disordered language as a core symptom of ASD. Specific language impairment (SLI) occurs when "a child fails to develop spoken language on a normal schedule, for no obvious reason" (Bishop, 2010, p. 618), and has continued to be discussed as a core feature of ASD (Conti-Ramsden, Simkin, & Botting, 2006; Loucas et al., 2008); however, there is very little research on the prevalence of SLI that occurs in children with ASD because of the controversy in diagnosing a child with ASD *and* SLI (Conti-Ramsden, Simkin, & Botting, 2006; Loucas et al., 2008). Although, one study estimated that up to 50% of children with ASD were nonverbal (Jang & Matson, 2015).

Seizures

The prevalence of a comorbid diagnosis of seizures or epilepsy ranges from 8% to 30% in the ASD population (Amiet et al., 2008; Tuckman & Cuccaro, 2011). The additional diagnosis of ID increases the risk that a child with ASD will also develop epilepsy, and there is positive relationship among the severity of ID symptoms and epilepsy development (Tuckman & Cuccaro, 2011). Twenty-one percent of children with ASD and ID also have epilepsy whereas only 8% of children with ASD without ID have epilepsy (Amiet et al., 2008). The onset of epilepsy occurs before the age of 5 and during adolescence (Tuckman & Cuccaro, 2011; Bauman, 2010), and typically requires scans and tests for diagnosis and possible surgery for treatment. The ages of onset may help explain why children with ASD are in more frequent contact with inpatient and outpatient hospital facilities compared with children who are typically developing (Venkat et al., 2012; Atladóttir et al., 2012; Scarpinato et al., 2010). Another reason children with ASD may be in frequent contact with outpatient surgery units is because some children with ASD require general anesthesia for procedures, such as: regular teeth cleanings, magnetic resonance imaging (MRI) scans, electroencephalographies (EEGs), and hearing tests, whereas children who are typically developing may not need anesthesia for these procedures. Because of the need for medical tests related to the comorbid diagnoses of ASD, it is important that healthcare professionals and medical staff know how to best work with this population.

Challenging Behavior

A common symptom displayed by children with ASD is challenging behavior. Challenging behaviors are behaviors that are physically dangerous, not accepted by society, and/or disruptive to education (Jang, Dixon, Tarbox, & Granpeesheh, 2011). Examples of challenging behavior include aggression, tantrums, noncompliance, property

destruction, self-injury, and restrictive, repetitive, or stereotyped behaviors (Matson & Nebel-Schwalm, 2007; O'Reilly et al., 2010; Jang et al., 2011). Jang et al. (2011) examined the prevalence of challenging behavior and found that the severity of ASD symptoms alone increased the probability that challenging behaviors occurred. Furthermore, these authors found a 94% prevalence rate of challenging behaviors among children with ASD (Jang et al., 2011). With this high prevalence rate, it is expected that medical staff caring for children with ASD are very likely to be faced with frequent challenging behaviors by this patient population.

In the outpatient surgery unit, challenging behavior can harm the patient, their parents, medical staff, and other patients and families who come into contact with the patient. Challenging behaviors are especially dangerous when medical staff need to be in close proximity to the patient (i.e., giving medication or checking vital signs). Another consideration for children exhibiting challenging behavior is the size and strength of the child. Young children exhibiting challenging behavior can look like tantrums, which are typical for this developmental level and usually physically manageable by parents and medical staff. The risk of staff becoming injured by a young child is most likely lower when compared with older children and adolescents. Adolescents exhibiting challenging behavior can be far more aggressive and destructive in their behaviors because they have an adult-sized body and adult strength. For example, one parent had a concussion because her adolescent had head-butted her the week prior to coming to the outpatient surgery unit. Age groups, specifically early childhood (ages 2–5 years), middle childhood (ages 6–12 years), and adolescence (13 years and older), should be considered when developing the intervention program. Given the prevalence rate of challenging behavior, not only is it important to implement an intervention program for the psychosocial needs

of the patients with ASD, it is also necessary to implement an intervention that ensures the safety of patients, their parents, and the medical team.

STRESS AND COPING

In Lazarus and Folkman's (1984) cognitive theory of stress and coping, stress is defined as "a particular relationship between a person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being" (p. 19). To be considered a stressor, an individual must first appraise the situation as troubling to one's psychosocial or physical health (e.g., breathing in the anesthesia mask; Lazarus & Folkman, 1984; Goldberger, Mohl, & Thompson, 2009). Once appraised as stressful, the secondary appraisal occurs when the individual searches for resources available to cope with the stressful situation (Lazarus & Folkman, 1984; Goldberger et al., 2009). Some of the symptoms of ASD (i.e., communication difficulties, hyper-reactivity to environmental stimuli) make this population especially vulnerable to stressors (Baron, Groden, Groden, & Lipsitt, 2006). Because children with ASD are thought to appraise daily experiences as stressful (i.e., change in routine; APA, 2013; CDC, 2016; Seid, Sherman, & Seid, 1997; Baron et al., 2006; Kerns, Newschaffer, & Berkowitz, 2015), it is likely that this population would appraise the hospital–a place where typically developing children experience stress–as stressful.

There are many ways that individuals cope with stress; however, some coping strategies may not be effective for children with ASD. Coping is a "dynamic, constantly changing" process, requiring reappraisal of ongoing stressors to promote emotion-focused and problem-focused coping (Goldberger et al., 2009, p. 165; Folkman, 1997). *Emotion-focused coping* is directed toward the regulation of one's emotional responses to a potentially stressful circumstance. For a child with ASD, emotion-focused coping may take the form of a restrictive, repetitive behavior (e.g., child rocking back-and-forth to

avoid a meltdown when in close proximity to a physician). *Problem-focused coping* is directed toward managing or changing the situation to handle the stressor. An example of such coping includes providing a picture schedule for a child with ASD to communicate the sequence of events for a medical visit. (Picture schedules have been used in schools to increase children with ASD's understanding of what is expected of them, and have also shown promise in reducing anxiety for children with ASD in medical environments [Chebuhar, McCarthy, Bosch, & Baker, 2013]. Child life specialists commonly use picture schedules to facilitate a child's understanding of upcoming medical procedures).

In addition, coping may be influenced by one's past (positive or negative) experiences and by changing circumstances within the environment (Goldberger et al., 2009). If a child had a stressful medical experience and then returns to a medical environment, the child is likely to arrive with heightened stress. For example, a dentist was unable to complete a routine teeth cleaning on a patient with ASD, so four dental assistants were required hold the patient down (one assistant for each appendage). The patient continued struggling so the dentist administered nitrous oxide (laughing gas) through a mask to continue with the teeth cleaning. After several minutes of struggling with the patient, the dentist was still unable to complete the teeth cleaning so the patient was scheduled for a teeth cleaning under general anesthesia at the hospital. When the child arrived at the hospital, the child remembered his previous experience of being held down while breathing in a mask and immediately panicked when seeing the anesthesia mask used for induction at the hospital. Children with ASD are at increased risk for experiencing traumatic events during medical visits or procedures when compared to their typically developing peers (Kerns, Newschaffer, & Berkowitz, 2015). Therefore, it is important for interventions to be individualized, taking into account the child's

previous traumatic healthcare experiences, in order to help children with ASD adaptively cope with an upcoming medical procedure.

There is a large body of research that uses Lazarus and Folkman's (1984) theoretical framework to examine how individuals appraise and cope with stressful stimuli; however, there is scant literature on the way children with ASD appraise and cope with stressful stimuli (Baron et al, 2006). It is thought that some of the restrictive, repetitive behaviors exhibited by children with ASD are driven by stress or anxiety (Gillott, Furniss, & Walter, 2001) and may be used as a coping technique for children with ASD (Baron et al., 2006). However, more research is needed to understand how children with ASD appraise and cope with stressors in their environment, specifically a frightening environment such as the hospital. The present intervention program was aimed at minimizing children with ASD's exposure to events and situations in the outpatient surgery unit that might be sources of stress.

Addressing the Hospital-Linked Stress Experienced by Typically Developing Children Versus Children with Autism Spectrum Disorder

Studies from the past few decades have reported that children experience stress and anxiety in the hospital setting (Gaynard et al., 1998; Thompson, 2009; Thompson & Stanford, 1981). Some of the negative outcomes for children who experienced stressful hospital events included decreased cooperative behavior, eating and sleeping disturbances, post-traumatic stress, and extended recovery time after surgery (Gaynard et al., 1998; Child Life Council, 2007; Skipper & Leonard, 1968; Thompson, 2009; Thompson & Stanford, 1981). In 1983, the *Association for the Care of Children's Health* (now, the Child Life Council) conducted a research study on the effectiveness of an experimental child life program in the surgery department at Phoenix Children's Hospital (Gaynard et al., 1998; Thompson, 2009). Children who received the experimental child

life services, which was developmentally appropriate education for children before their surgery, showed "less emotional distress, more effective coping, greater understanding of hospital experiences, and better overall and post-hospital adjustment" than the children in the control group (Gaynard et al., 1998, p. 2; Thompson, 2009).

However, few studies have been published about treating the psychosocial needs of children with ASD in hospitals or outpatient surgery units (Davit et al., 2011; Bagshaw, 2011). Previous research on psychosocial treatments for children with ASD in the outpatient surgery unit consisted of single case studies that make recommendations for best practice. Many studies described suggestions for healthcare providers to consider when caring for patients with ASD (Venkat et al., 2012; Souders, Freeman, DePaul, & Levy, 2002; Davit et al., 2011; Scarpinato et al., 2010; Nelson & Amplo, 2009; Shah et al., 2009; Christiansen & Chambers, 2005; van der Walt & Moran, 2001; Seid, Sherman, & Seid, 1997; Rainey & van der Walt, 1998), but these studies were mere descriptions of how physicians provided care for one child with ASD. Although, an Australian facility reported keeping a database of interventions used for patients with ASD, such as communicating with the child's family prior to admission and the flexibility to individualize the admission process and anesthetic plan for each child (Rainey & van der Walt, 1998; van der Walt & Moran, 2001); however, none of these studies were based on the assessment of a standardized intervention protocol for children with ASD. In general, most of these studies concluded that children with ASD were challenging, difficult, and frustrating for medical staff (Werner, 2011; Shah et al., 2009), but they provided no measure of the children with ASD's stress levels in the healthcare setting. Although these case studies and their recommendations helped to inform the present intervention program for this clinical population, to date, there has been no formal research study on implementing an intervention program with a relatively large sample size. Given the

stress and anxiety that children with ASD are known to exhibit in new environments (CDC, 2016; White, Oswald, Ollendick, & Scahill, 2009), and particularly in healthcare environments (Bagshaw, 2011; Scarpinato et al., 2010; Davit et al., 2011; Christiansen & Chambers, 2005), it was important to develop an intervention protocol aimed at lowering the stress levels these children experience in the healthcare environment and to empirically validate the effectiveness of that intervention (Nelson & Amplo, 2009).

Stress in Parents of Children with Autism Spectrum Disorder

Several studies have measured the stress levels of parents who have a child with ASD. When validating the Autism Parenting Stress Index (APSI), Silva and Schalock (2012) found that parents who had a child with ASD were four times more stressed than parents of typically developing children and two times more stressed than parents of children with other developmental disabilities. Also, children with severe ASD symptoms were related to increased stress for parents when compared to children with mild ASD symptoms (Phetrasuwan & Miles, 2009; Hall & Graff, 2011; Jang et al., 2011; Duarte, Bordin, Yazigi, & Mooney, 2005). Severe ASD symptoms included impairment of the child's adaptive behavior and display of challenging behaviors by the child (Phetrasuwan & Miles, 2009; Hall & Graff, 2011; Jang et al., 2011; Duarte et al., 2005). In general, parents of children with ASD reported higher levels of stress than parents of typically developing children, children with other developmental disabilities, and children with special healthcare needs (Silva & Schalock, 2012; Schieve, Blumberg, Rice, Visser, & Boyle, 2007; Duarte et al., 2005). Because there has been a relationship among ASD symptom severity (i.e., challenging behaviors) and parenting stress, interventions aimed at lowering the incidence of challenging behaviors could also lower the amount of stress in parents who have a child with ASD. Also, there may be a bidirectional relationship among stress experienced by parents and their child with ASD. Therefore, it is important

to determine how to decrease the amount of stress parents may experience in the healthcare environment because this could also decrease the stress and anxiety experienced by their child and possibly the medical staff caring for the child with ASD (Bagshaw, 2011; Lindberg, von Post, & Eriksson, 2012).

Stress in Medical Staff Caring for Children with Autism Spectrum Disorder

Caring for patients is considered stressful for all medical staff (Lökman, Gabriel, & Nicolson, 2011; Vowels, Topp, & Berger, 2012; Kain et al., 2002). However, this is especially true for medical staff who care for patients with ASD or other developmental disabilities (Shah et al., 2009; van Oorsouw, Embregts, Bosman, & Jahoda, 2010). Although there is sparse literature, Werner (2011) found that future healthcare professionals (i.e., nursing and social work students) reported that caring for patients with ASD was "difficult, challenging, and frustrating" (p. 131), particularly when patients exhibited challenging behavior (i.e., noncompliance with checking vital signs every hour, yelling, or spitting) (Shah et al., 2009; van Oorsouw et al., 2010). Nonetheless, these same healthcare professionals also reported that working with the ASD population was "rewarding, important, and an opportunity to develop personally and professionally" (p. 131). Lökman and colleagues (2011) suggested a bidirectional relationship among the stress experienced by healthcare staff and the stress experienced by patients with ASD, and recommended that interventions be aimed at decreasing the amount of stress healthcare professionals experience at work as well as decreasing the amount of stress for patients with ASD. Due to the increased prevalence of ASD (CDC, 2016; Venkat et al., 2012; Atladóttir et al., 2012; Scarpinato et al., 2010), healthcare professionals are obligated to be comfortable taking care of patients with ASD. A psychosocial intervention that targets environmental stressors for patients with ASD and provides

education about ASD for medical staff could help reduce the stress experienced by medical staff and their patients with ASD.

PATIENT- AND FAMILY-CENTERED CARE HEALTHCARE DELIVERY MODEL

Patient- and family-centered care (PFCC) is a healthcare delivery model that focuses on the mutually beneficial partnerships among patients, family members, and multidisciplinary medical staff (Institute of Patient and Family Centered Care [IPFCC], 2010). The four core concepts of PFCC include: (1) respect and dignity, (2) information sharing, (3) participation, and (4) collaboration between patients, family members, and medical staff (IPFCC, 2010; Kuo, Houtrow, Arango, Kuhlthau, Simmons, & Neff, 2012). Patient- and family-centered care defines the family as two or more persons with a biological or emotional connection (i.e., patients or parents of minors define who are members of their family regardless of biological relation; IPFCC, 2010). Patient- and family-centered care posits that patients and family members should be a part of all aspects of healthcare services, including: program development (e.g., creating a psychosocial intervention for patients with ASD), delivery of care (e.g., new guidelines set for parents visiting their child in the recovery room), professional education (e.g., a family advisor spends 10 minutes at new employee orientation explaining the experience she and her child had at the hospital), and facility design (e.g., family advisors worked with the contractors of a new hospital to design patient room layouts; Kuo et al., 2010). Research has shown that the provision of PFCC healthcare services were associated with better health outcomes and higher levels of patient and family satisfaction scores (IPFCC, 2010; Epstein & Street, 2011; Rathert, Wyrwich, Boren, 2013).

Patient- and family-centered care recognizes that the family is the constant in a patient's life and that all families are competent and capable of participation in their family member's healthcare needs (Child Life Council, 2016; Kuo et al., 2012). Child life

specialists advocate for PFCC in the healthcare environment and seek to empower parents to actively participate in their child's care (Child Life Council, 2016). For instance, instead of providing positive diversion (e.g., blowing bubbles) for a patient during a blood draw, the child life specialist hands the bubbles to the parent, thereby empowering the child's parent to blow bubbles for the child and actively participate in the child's ability to cope with stress procedures. The child life specialist recognizes that he or she may not be there for every blood draw or medical procedure for this child, but the parent (or family member) is the constant in the child's life and will be there for all of the child's upcoming medical procedures. The following intervention program and research study implementation were based on the core concepts of the PFCC healthcare delivery model.

AIMS OF THE PRESENT STUDY

Given the pervasive symptoms of ASD, visiting the hospital (and undergoing a procedure with general anesthesia) is particularly stressful for this patient population. The psychosocial interventions provided by child life specialists (e.g., developmentally appropriate education about medical procedures) for typically developing children have not been consistently effective for patients with ASD and, therefore, an intensive psychosocial intervention that could be individualized and planned prior to the day of the child's procedure could be an effective way to help children with ASD cope with the hospital environment. In addition, because the literature on children with ASD undergoing a procedure with general anesthesia is primarily case studies, there was a need to conduct an intervention study with a relatively large sample size that could be carefully evaluated.

This study was the first quasi-experimental study that included a patient- and family-centered psychosocial intervention program for pediatric patients with ASD in an

outpatient surgery unit and also included an educational intervention for perioperative nursing staff.

Aim 1 of the present study was to design an intervention to minimize the stress children with ASD experience while patients in an outpatient surgery unit. The intervention was designed based on recommendations from both staff and parents and from findings in the small extant literature to date.

Aim 2 was to examine whether such an intervention could be feasibly and successfully implemented in an outpatient surgery unit.

Aim 3 was to evaluate whether the intervention was effective at lowering the stress levels of and the amount of challenging behaviors for pediatric patients with ASD in an outpatient surgery unit.

Aim 4 was to evaluate whether the intervention was effective at lowering the stress levels of both the parents of children with ASD and the nursing staff who cared for these children.

The idea for this study originated from the outpatient surgery PFCC committee, where parents and medical staff both identified incidences of severe stress and aggression in patients with ASD undergoing an outpatient procedure with general anesthesia. Specifically, one child life specialist noted the difficulty in helping patients with ASD return to their baseline behavior when challenging behavior was already shown upon arrival to the surgery waiting room. After this patient care problem was established, the committee brainstormed possible solutions that could be offered to patients with ASD and their families in order to accommodate any special needs. For example, one parent reported that forcing her son to change into a hospital gown before his procedure was what triggered his challenging behaviors and asked if her son could wear his clothes from home to the operating room. Having a variety of medical staff who served on the PFCC

committee (e.g., surgeons, anesthesiologists, nurse anesthetists, nurses from each area in the surgery department, child life specialists, scrub technicians, imaging technicians, and surgery department management staff) helped to ensure that any accommodations discussed within the committee would not compromise patients' safety in the delivery of medical care (e.g., a patient could wear clothes from home to the operating room if there were no metal buttons or zippers).

The intervention created for this study was called the Special Needs Assessment and Plan (SNAP) intervention program. For this study, the SNAP intervention program was implemented for a sample of pediatric patients with ASD in the outpatient surgery unit at a pediatric hospital facility in the southern United States. A group of children with ASD who did not receive the intervention was used as a comparison group for the purposes of the evaluation. This study tested the following hypotheses about the implementation of the SNAP intervention program:

1. the parent-reported stress levels of pediatric patients with ASD in the intervention group will be lower than the parent-reported stress levels of pediatric patients with ASD in the comparison group;
2. the frequency of challenging behaviors exhibited by pediatric patients with ASD in the intervention group will be lower than the frequency of challenging behaviors exhibited by pediatric patients with ASD in the comparison group;
3. the self-reported stress levels for parents of patients with ASD in the intervention group will be lower than the self-reported stress levels for parents of patients with ASD in the comparison group; and
4. the self-reported stress levels for the perioperative nurses who directly cared for these patients will be lower than the self-reported stress levels for perioperative nurses in the comparison group.

Method

PARTICIPANTS

Patients

For both phases, pediatric patients were eligible to be in the study if they were at least two years of age, scheduled for an outpatient procedure with general anesthesia at the site of the study, and diagnosed with ASD under either DSM-V or DSM-IV-TR diagnosis criteria. The DSM-V diagnosis included autism spectrum disorder. The DSM-IV-TR diagnoses included Asperger's disorder, autistic disorder, or PDD-NOS diagnoses.

The comparison group included 48 patient participants (M = 9.67 years, SD = 5.65 years) who ranged from two to 21 years of age. Sixty-nine percent of comparison group patient participants were male. Patient participants were 52% White, 23% Hispanic/Latino(a), 11% Black, and 14% Asian/Other. Common comorbid diagnoses included lack of speech or speech delay (58%), developmental delay (36%), seizures or epilepsy (38%), and anxiety (9%). Common procedures that comparison group participants received under general anesthesia included magnetic resonance imaging (52%), electroencephalogram hook up (25%), dental restorations (29%), and surgical procedures (23%). Some participants had several procedures under general anesthesia. There was a 98% response rate (50 out of 51 parents) for patient and parent/legal guardian participation in the comparison group. One patient–parent/legal guardian dyad was dropped due to an incomplete consent form. Another patient–parent/legal guardian dyad was dropped due to enrollment in both the comparison and intervention groups.

The intervention group included 48 patient participants (M = 9.87 years, SD = 4.92 years) who ranged from two to 20 years of age. Eighty-one percent of the intervention group patient participants were male. Patient participants were 48% White, 33% Hispanic/Latino(a), 13% Black, and 6% Asian/Other. Common comorbid diagnoses

included lack of speech or speech delay (36%), developmental delay (19%), seizures or epilepsy (21%), and anxiety (13%). Common procedures that intervention group participants received under general anesthesia included magnetic resonance imaging (38%), electroencephalogram hook up (10%), dental restorations (27%), and surgical procedures (42%). Some participants had several procedures under general anesthesia. There was a 96% response rate (50 out of 52 parents) for patient and parent/legal guardian participation in the intervention group. One patient–parent/legal guardian dyad was dropped due to insufficient paperwork for ASD diagnosis. As previously mentioned, one patient–parent/legal guardian dyad was dropped due to enrollment in both the comparison and intervention groups.

Parents and Legal Guardians

The comparison group included 47 parent/legal guardian participants (M = 39.14 years, SD = 8.95 years) who ranged from 24 to 62 years of age; one professional caregiver provided consent for two patient participants enrolled in the study. Ninety percent of comparison group parent/legal guardian participants were female and 94% of parent/legal guardian participants were the mother or father of the patient. The remaining parent/legal guardian participants were legal guardians or professional caregivers of the patient participants. Parent/legal guardian participants were either married (60%), divorced or separated (25%), or never married (15%). The education levels of the comparison group parent/legal guardian participants included Bachelor's or graduate degree (42%), some college or Associate's degree (45%), high school graduate or equivalent (8%), and some high school (5%). Four percent of comparison group parent/legal guardian participants were Spanish-speaking.

The intervention group included 47 parent/legal guardian participants (M = 40.00 years, SD = 5.87 years) who ranged from 27 to 51 years of age; one parent provided

consent for two patient participants enrolled in the study. Eighty-five percent of intervention group parent/legal guardian participants were female and 98% of parent/legal guardian participants were the mother or father of the patient. The remaining parent/legal guardian participant was a legal guardian or professional caregiver of the patient participant. Parent/legal guardian participants were either married (70%), divorced (21%), or never married (9%). The education levels of the comparison group parent/legal guardian participants included Bachelor's or graduate degree (43%), some college or Associate's degree (43%), high school graduate or equivalent (12%), and some high school (2%). Eleven percent of intervention group parent/legal guardian participants were Spanish-speaking.

Nursing Staff

Fifty-eight nurse participants, ranging from 28 to 63 years of age (M = 44.8 years, SD = 11.0 years), cared for patient participants in both the comparison and intervention groups. They were employed as either a pediatric preoperative, operating room, imaging, interventional radiology, or post-anesthesia care unit nurse, and provided consent to participate in the study. Ninety-one percent of nurse participants were female and 84% were full time employees. The nurse participants averaged 20.1 years of nursing experience (*range* = 4–38 years, SD = 10.0 years). Nurse participants were White (74%), Hispanic/Latino(a) (16%), or Black/Other (10%), and married (50%), divorced or separated (28%), or never married (22%). There was a 98.3% response rate for nurse participants (one nurse declined to participate).

PROCEDURE

The pilot study included two phases: (1) comparison group data collection and (2) intervention group data collection. Both phases collected data on patients with ASD, their

parents or legal guardians, and the perioperative nurses who directly cared for patients enrolled in the study. Comparison group data collection was completed in four months. There was a four month break in data collection while the research team provided three 30 minute education sessions for perioperative nursing staff. Then, intervention group data collection was completed in 10 months.

The Institutional Review Boards of both the hospital facility and the University of Texas at Austin approved this study. This study was also approved by the hospital's clinical research operation review team, the director and managers of the outpatient surgery unit, and the director of quality improvement at the pediatric hospital.

Recruitment

One or two days prior to every patient's procedure with general anesthesia, the pre-admission and testing (PAT) nurse called the patient's parent or legal guardian to discuss the patient's medical history and pre-operative plans for the patient. If a patient was diagnosed with ASD, the PAT nurse notified the child life specialist by phone or email. Each day, the child life specialist also reviewed the next day's outpatient surgery schedule and each patient's admission history form written by the PAT nurse to ensure that all patients with an ASD diagnosis had the opportunity to participate in the pilot study. The first 103 patients with ASD were invited to participate in the study. One parent/legal guardian declined to participate in the comparison group and two parents/legal guardians declined to participate in the intervention group.

Nursing Staff Recruitment

Nurses were recruited to participate in the study during three departmental staff meetings. Each nurse attended only one of the three meetings. The research team introduced the pilot study, reviewed the informed consent document, and discussed

comparison group procedure. Nurses were also asked to attend one education session with the research team after completion of comparison group data collection.

Comparison Group Procedure

After the patient was under general anesthesia, the child life specialist met the parent or legal guardian in the waiting room and invited him or her to participate in the study. Informed consent and HIPAA release forms were reviewed with the parent. (Patient assent was attempted for some participants prior to their procedure, but due to participant diagnoses and parental discretion most patient participants were unable to provide study assent). A folder was given to the parent that contained the informed consent document, the HIPAA release form, and three surveys: (1) Patient and Caregiver Stress Survey, (2) Behavior Problem Inventory-Short Form (BPI-S), and (3) Autism Parenting Stress Index (APSI). Parents completed the forms and surveys during the patient's procedure with general anesthesia (see Figure 1), placed the forms in a sealed manila folder, and turned them in at the front desk of the outpatient surgery unit or to the child life specialist directly. The comparison group parent participants did not complete the SNAP Intervention Survey.

Nursing Staff

A clear, plastic folder, which included four blank Staff Stress Surveys and a manila folder, was placed within the patient participant's medical chart. For both phases of the study, medical staff completed the Staff Stress Survey after directly caring for the patient enrolled in the study. After completing one survey, the nurse then placed their survey in the manila folder within the plastic folder. (Each nurse placed their survey inside the manila folder upon completion so that the remaining nurses were unable to view their responses). A total of four surveys were completed for each patient enrolled in

the study (see Figure 1). Typically, four different nurses completed the surveys for each patient enrolled in the study; however, occasionally, three nurses completed four surveys for a patient because the preoperative and post-operative discharge nurse were the same person.

Intervention Group Procedure

Over the telephone, at least one day prior to the patient's procedure, the child life specialist introduced herself and the pilot study to the parent, invited the parent to participate in the study, and obtained over-the-phone, verbal consent to participate in the study. Then, the child life specialist facilitated a semi-structured interview, guided by the SNAP Intervention Survey, with the parent or legal guardian over the telephone. The second part of the survey and parent interview included the creation of an individualized coping plan for the patient participant. A written description of the patient's individualized coping plan was typed and printed onto bright green cardstock paper and placed in the front of the patient's chart, prior to the patient's arrival at the hospital. When necessary, the child life specialist verbally contacted the anesthesia department, scheduling personnel, and pre- and post-operative charge nurses to coordinate the patient's coping plan. On the day of the patient's procedure, a different child life specialist (not the child life specialist who completed the phone call with the parent) implemented the patient's individualized coping plan, collaborating with multidisciplinary staff in the outpatient surgery unit.

After the patient was under general anesthesia, the child life specialist (who completed the phone call) met the parent or legal guardian in the waiting room and confirmed the parent's interest in study participation. Informed consent and HIPAA release documents were reviewed with the parent. (Patient assent was attempted for some participants prior to their procedure, but due to participant diagnoses and parental

discretion most patient participants were unable to provide study assent). A folder was given to the parent that contained the informed consent document, the HIPAA release form, and four surveys: (1) Patient and Caregiver Stress Survey, (2) Behavior Problem Inventory-Short Form (BPI-S), (3) Autism Parenting Stress Index (APSI), and (4) SNAP Intervention Survey. (The comparison group parent participants completed all of the same forms and surveys except the SNAP Intervention Survey). Parents completed the forms and surveys during the patient's procedure with general anesthesia (see Figure 2), placed the forms in a sealed manila folder, and turned them in at the front desk of the outpatient surgery unit or to the child life specialist directly.

Nursing Staff

During three departmental staff meetings, the child life specialist facilitated a 30-minute education session on the signs and symptoms of children with ASD and how these symptoms could be amplified in the outpatient surgery unit (see Appendix A). Nurses attended one of the three education sessions. The child life specialist introduced nursing staff to the format of the individualized coping plans that would be created by the child life specialist and parent/legal guardian at least one day prior to the patient's procedure. Nurses were asked to use the individualized coping plan as a guide and to modify the coping plan to fit the patient's needs on the day of the procedure. Nurses followed the same procedure of completing the Staff Stress Surveys for the intervention group as they did for the comparison group (see Figure 2).

MEASURES

Patient and Caregiver Stress Survey

The *Parent and Caregiver Stress Survey* was created for this study to assess the parent's perception of their stress level on a typical day, upon arrival to the outpatient

surgery unit, and during time spent in the outpatient surgery unit. The survey also assessed the parent's perception of his or her child's stress level on a typical day, upon arrival to the outpatient surgery unit, and during time spent in the outpatient surgery unit. The parent's stress perception ratings were each scored on a five-point Likert scale from one (*no stress*) to five (*high stress*). This survey included two open-ended questions concerning what was done well and what could be improved during their experience in the outpatient surgery unit. The survey also assessed the types of challenging behaviors exhibited by the patient, if any, in the outpatient surgery unit. Parents completed this survey on the day of their child's procedure (see Appendix B).

Behavior Problem Inventory-Short Form

The *Behavior Problem Inventory-Short Form* (BPI-S) assesses the frequency and severity of 30 types of challenging behavior exhibited by the patient at home (Rojahn et al., 2012). It was modified from Rojahn, Matson, Lott, Esbensen, and Smalls's (2001) 52-item Behavior Problem Inventory. The behaviors are separated into three sections: (1) self-injurious, (2) aggressive, and (3) stereotypical behaviors. The scores for each challenging behavior category were totaled for a final score. Rojahn and colleagues (2012) conducted a study on the reliability and validity of this survey and found that the BPI-S proved to have sound psychometric properties. Parents completed this survey on the day of their child's procedure.

Autism Parenting Stress Index

The *Autism Parenting Stress Index* (APSI) contained 13 common experiences that parents of children with ASD frequently encounter (Silva & Schalock, 2012). The index asked the parent to choose how stressful each item was for them using a five point Likert scale from 0 (*not stressful*) to 4 (*so stressful sometimes we feel we can't cope*; Silva &

Schalock, 2012). The scores were totaled for a final score. In the initial study on the reliability and validity of the APSI, Silva and Schalock (2012) found that the APSI had sound psychometric properties. Parents completed this survey on the day of their child's procedure.

Staff Stress Survey

The *Staff Stress Survey* was created to assess the nurse's self-reported perception of stress on a typical day at work, on a stressful day at work, and when working with the patient enrolled in the pilot study. The stress perception ratings were each scored on a five-point Likert scale from one (*no stress*) to five (*high stress*). Nurses completed this survey after directly caring for a patient enrolled in the study, specifically at four times during the patient's time in the outpatient surgery unit: (1) pre-operative nurse, (2) operating room, imaging, or interventional radiology nurse, (3) post-anesthesia care unit nurse, and (4) post-operative discharge nurse (See Figures 1 and 2).

This survey also included two checklists: (1) accommodations made for the patient and (2) types of challenging behaviors exhibited by the patient, while caring for the patient in the outpatient surgery unit. The accommodations checklist was used to determine if nurses were already making accommodations for patients with ASD prior to the intervention phase as well as to confirm fidelity of the intervention program. The challenging behaviors checklist was used to complement the parent participant's self-reported measure of challenging behavior displayed by their child in the outpatient surgery unit. (see Appendix C).

Special Needs Assessment and Plan (SNAP) Intervention Survey

The *SNAP Intervention Survey* was administered by phone one to two days prior to each patient's procedure by a child life specialist, and then each parent/legal guardian

participant in the intervention group completed this survey during their child's procedure with general anesthesia. The goal of the survey was to have parents identify potential stressors for the patient in the outpatient surgery unit and to create a coping plan to be implemented on the day of the patient's procedure. This survey consisted of 10 open-ended questions along with two checklists for the parent to answer about their child (see Appendix D).

This survey first assessed the patient's previous medical experiences (e.g., doctor or dentist appointments, hospital visits). If the parent reported the patient was "nervous" or "anxious" during previous medical experiences, the parent was prompted to answer the question, "Was there a specific experience that severely frightened or stressed your child?" Then, the parent was asked to describe the stressful medical experience. Because children are known to display a significant change their behavior after enduring a traumatic medical experience (Gaynard et al., 1998; Child Life Council, 2007; Skipper & Leonard, 1968; Thompson, 2009; Thompson & Stanford, 1981), this question was used to gauge the patient's baseline behavior in the medical environment and also to understand the patient's psychosocial history of healthcare experiences.

Next, parents were asked about specific triggers that may increase the patient's stress level or increase the incidence of challenging behavior displayed by the patient at the hospital. Based on many years of interaction with patients who have ASD and discussion with their parents, the research team created a checklist of possible triggers for this patient population. Some triggers on the checklist included: changing into the hospital gown, checking blood pressure, seeing a hospital stretcher, and viewing medical staff in scrubs or white coats. The child life specialist did not read the triggers from the checklist to the parent during the phone interview unless the parent said, "I don't know."

The child life specialist described several triggers commonly seen in the outpatient surgery unit to prompt a response from the parent.

Then, parents were asked about the behaviors the patient displays when having a tantrum or meltdown. Another checklist of common challenging behaviors was listed on the survey; although, the child life specialist did not read the behaviors from the checklist to the parent during the phone interview unless the parent said, "I don't know." The child life specialist next asked, "Does your child ever become aggressive toward himself or others?" Knowing if the patient's behavior was likely to become aggressive toward him- or herself or others helped the child life specialist prioritize the individual needs for the patient. For example, if a patient was constantly hitting his or her head on the wall, this was considered a priority behavior compared to the child's repetitive clapping. Whenever the patient, family member, or staff member could become injured from the patient's behavior, this behavior became the focus of the coping plan. Stereotyped or repetitive behaviors were not targeted as threatening for the coping plan because these behaviors were thought to be a coping strategy for children with ASD (Baron et al., 2006).

The next four questions asked the parent about the type of environment that was most calming to the patient, as well as what the patient liked to do for fun at home. This allowed the child life specialist to understand typical experiences for the patient at home and assisted in the creation of a pre-operative environment that could smooth the patient's transition from home to the hospital. For example, if a patient particularly liked trains, the child life specialist placed toy trains in the patient's preoperative room to facilitate positive diversion from the hospital environment. Or, if a patient was sensitive to sound, the child life specialist assigned the patient to a pre-operative room with low foot traffic to cut out unnecessary background noise for the patient.

The next question asked the parent how the patient communicated with the parent. Because up to 50% of children with ASD are nonverbal or speech delayed (Jang & Matson, 2015), it was important to learn how the patient communicated with the parent. The communication information was added to the patient's individualized coping plan so that medical staff would know how to communicate with the patient. This question also gauged the likelihood that a patient would display challenging behavior as a means of communication.

The next question asked if the parent and patient had been to the outpatient surgery unit at the site of the study prior to the upcoming procedure with general anesthesia. If so, the child life specialist prompted the parent to discuss "what went well" and "what didn't go well" during their previous visit to the outpatient surgery unit. After this question, then the formation of the patient's individualized coping plan began: The parent was asked what could be done to minimize the stress that the patient and parent might experience at the outpatient surgery unit.

Some examples of individualized coping plans were: escorting the patient and parent to a private, preoperative room so the patient did not have to spend time in the waiting room; choosing a room in a quiet area with minimal hallway traffic; minimizing the number of medical staff members present in a room to only two at a time; not checking vital signs upon arrival; allowing the patient to remain in their clothes from home rather than changing into the hospital gown; providing developmentally appropriate activities in the patient's preoperative room; having the parent present for the patient's anesthesia induction; providing low lighting in the operating room; and ensuring minimal talking among staff during the patient's anesthesia induction. Common post-operative accommodations for the patient included: selecting a quiet post-operative bay to minimize auditory stimulation; allowing early parental presence in the recovery room;

discharging the patient from the outpatient surgery unit in the recovery room (instead of transitioning to the preoperative area for discharge–which is the typical patient flow); and removing the intravenous catheter early, when appropriate. (see Appendix E for an example of an individualized coping plan).

Electronic Medical Record

Data from the electronic medical record were collected on the patient participants for both phases of the study. All clinical notes from the day of the procedure were collected, including physician orders, anesthesia records, health history, nursing records, parent preoperative and discharge instructions, medications administered, operative and imaging impression reports, blood work results (if ordered by physician), vital signs (e.g., blood pressure, heart rate, temperature, and oxygen saturation), demographic variables, and health insurance information. Previous chart notes from support services (i.e., child life services, expressive therapies, social work, and chaplain services) were also collected.

Operating Room Control Board

Using the operating room control board tagging system, data were collected on the amount of time the patient spent in each area of the outpatient surgery unit. This data was collected during both phases of the study.

ANALYSIS

To evaluate the efficacy of the intervention program, univariate analysis of covariance (ANCOVA) models were used to compare the stress levels and the incidence of challenging behavior among patients in the comparison and intervention groups. ANCOVAs were also used to compare the stress levels of parents and nursing staff, separately, among the comparison and intervention groups. The APSI score, BPI-S score,

nonverbal diagnosis, and age groups (ages 2–5 years, ages 6–12 years, and ages 13 years and older) were tested as moderators for patients' total stress levels at the hospital, parents' total stress levels at the hospital, and nursing staff's stress levels when caring for patients with ASD using ordinary least squares regression analyses. An additional ANCOVA model was used to compare the amount of accommodations nursing staff made for patients in the comparison and intervention groups. All models controlled for language impairment and surgery procedure. Relevant models controlled for recovery room nurses' stress level on a typical day.

Results

Independent samples *t*-tests and chi-square analyses were estimated to determine how well the comparison and intervention group participants matched across various patient (Table 1) and parent/legal guardian characteristics (Table 2). Similar analyses were estimated for the groups of nursing staff (Table 3). Any variables that were significantly different were used as covariates in the focal analyses.

At the patient-level, the participants' age, gender, diagnoses, type of outpatient procedure, BPI-S score, APSI score, and stress level on a typical day were examined. Two significant differences emerged across the two conditions (see Table 1). First, parent-reported diagnosis of language impairment (nonverbal diagnosis or speech delay diagnosis) was significantly lower for the intervention group than the comparison group. Second, patients in the intervention group were also more likely to have a surgery procedure than patients in the comparison group. There were three marginal findings: The comparison group had more participants with (1) developmental delays and (2) epilepsy or seizures than the intervention group, and (3) the frequency and severity of stereotyped behaviors observed in participants on a regular basis was marginally higher for the comparison group than the intervention group. Unlike the patient-level factors, no significant differences were documented at the parent-level (see Table 2; age, gender, caregiver status, Spanish speaking preference, and stress level on a typical day).

Independent samples *t*-tests were also estimated to determine how well the comparison and intervention group nursing staff participants matched (see Table 3). Because the same group of nurses participated in the comparison and intervention groups, the nursing staff's stress level on a typical day at work and on a stressful day at work were only examined between groups. Results from these analyses revealed that the recovery room nurses reported significantly more stress on a typical day at work for the

intervention group than the comparison group. When applicable, recovery room nurses' stress level on a typical day was used as a covariate for the following analyses.

CORRELATIONS BETWEEN STRESS VARIABLES

Pearson *r*-correlations among patient, parent, and nursing staff stress levels were run separately for the comparison and intervention groups (see Table 4 and Table 5, respectively). Results from these bivariate analyses revealed that the comparison group patients' stress level upon arrival to the hospital and total stress level at the hospital were positively correlated with the parents' stress level upon arrival to the hospital, the parents' total stress level at the hospital, and the preoperative nurses' stress level. The patients' stress level upon arrival to the hospital was also positively correlated with their stress level on a typical day; however, this association did not exist among parents. In contrast, patients' stress level on a typical day was positively correlated with the parents' stress level on a typical day and negatively correlated with the operating room nurses' stress level. The operating room nurses' stress level was positively correlated with the recovery room nurses' stress level.

The intervention group patients' stress level upon arrival to the hospital and total stress level at the hospital were positively correlated with the parents' stress level upon arrival to the hospital, the parents' total stress level at the hospital, the parents' stress level on a typical day, and their stress level on a typical day. Both the patients' and parents' stress levels upon arrival to the hospital were positively correlated with the preoperative nurses' stress level. The patients' and parents' stress levels on a typical day were also positively correlated. The preoperative nurses' stress level was positively correlated with the post-operative discharge nurses' stress level.

CORRELATIONS BETWEEN CHALLENGING BEHAVIORS

Pearson *r*-correlations were also estimated separately for the comparison and intervention groups to examine parent-reported and nurse-reported challenging behaviors (see Table 6 and Table 7, respectively). For the comparison group, significant positive correlations were found among all parent-reported challenging behaviors and among all nurse-reported challenging behaviors; however, no significant correlations were documented between the parent- and nurse-reported challenging behaviors. Next, for the intervention group, significant positive correlations were found among all parent-reported challenging behaviors. Positive correlations were also found among the preoperative nurse-reported challenging behaviors, except aggressive behaviors were not correlated with the total amount of challenging behaviors. Similar to the comparison group, no significant correlations were found among the parent- and nurse-reported challenging behaviors.

FIDELITY OF THE INTERVENTION

Analysis of covariance (ANCOVA) models were used to compare the difference in nurse-reported accommodations made for patients with ASD between the comparison and intervention groups while controlling for the incidence of language impairment, surgery procedure, and recovery room nurses' stress level on a typical day (see Table 8). Preoperative and operating room nurses were significantly more likely to report accommodations made for patients with ASD in the intervention group when compared with accommodations reported for patients in the comparison group. Post-operative discharge nurses were marginally more likely to report accommodations for patients with ASD in the intervention group than the comparison group. Although the mean amount of accommodations was larger for the intervention group recovery room nurses, no significant difference was found among accommodations between the two groups.

PATIENTS' STRESS LEVELS

ANCOVAs were used to compare parent-reported patient stress levels among the comparison and intervention groups while controlling for the incidence of language impairment and surgery procedure (see Table 9). Results from these analyses revealed that there were no significant group differences in the patients' stress level at arrival to the hospital or the patients' total stress level at the hospital; however, patients ages 6–12 years old showed marginally lower levels of total stress at the hospital in the intervention group than in the comparison group.

Next, ordinary least squares (OLS) regression analyses were used to predict the patients' total stress level at the hospital using four moderators, separately. To test for moderation, interaction terms were created between the focal predictor (i.e., comparison versus intervention group) and the moderators (e.g., ASPI scores, BPI-S scores, nonverbal diagnosis, and patient age groups). If the interactions were statistically significant, interactions were plotted to interpret findings. Interactions in which the moderators were continuous variables (e.g., APSI scores and BPI-S scores) were probed and plotted at +/- 1 standard deviation to interpret the findings.

Results from these analyses revealed that parents' ASPI score did not moderate the effectiveness of the intervention for patients' total stress level at the hospital; however, patients' BPI-S score was found to moderate the efficacy of the intervention (see Table 10). After plotting the interactions, results revealed that patients with lower BPI-S scores showed significantly lower stress levels in the intervention group as compared with patients with lower BPI-S scores in the comparison group (see Figure 3). Although a similar trend was seen among patients with higher BPI-S scores, there was no significant difference between their stress levels as a function of the intervention.

Patients with a nonverbal diagnosis was found to moderate the efficacy of the intervention for patients' total stress level at the hospital (see Table 11). After plotting the interactions, results revealed that patients who were nonverbal showed marginally higher levels of stress in the comparison and intervention groups than patients who were verbal in the intervention group (referent group; see Figure 4). No significant difference was found in patients' stress level for those who were verbal as a function of the intervention. Therefore, the intervention only seemed to be effective for patients who were verbal.

Age groups were found to moderate the efficacy of the intervention for patients' total stress level at the hospital (see Table 12). After plotting the interactions, results from this analysis revealed that patients 13 years of age and older who were in the comparison and intervention groups showed significantly lower levels of stress than patients ages 6–12 years who were in the comparison group (referent group; see Figure 5). Patients ages 2–5 years who were in the comparison group were also found to show significantly lower levels of stress than patients ages 6–12 years who were in the comparison group whereas patients ages 2–5 years who were in the intervention group showed no significant differences in stress level than patients ages 6–12 years who were in the comparison group. Patients ages 6–12 years who were in intervention group showed significantly lower levels of stress than patients ages 6–12 years who were in the comparison group. Therefore, the intervention only seemed to be effective for patients ages 6–12 years, and patients ages 13 years and older were reported to have lower stress levels at the hospital regardless of their group status.

INCIDENCE OF CHALLENGING BEHAVIOR

ANCOVAs were used to compare the difference of parent-reported preoperative challenging behaviors exhibited by the patient and nurse-reported challenging behaviors exhibited by the patient between groups while controlling for the incidence of language

impairment and surgery procedure (see Table 13 and Table 14, respectively). No differences were found between groups among parent-reported preoperative challenging behaviors exhibited by their child; however, the mean for aggressive behavior in the intervention group was slightly lower than the mean for aggressive behavior in the comparison group.

Preoperative and post-anesthesia discharge nurses in the intervention group reported marginally lower levels of aggressive behavior than the comparison group. Although not statistically significant, operating room nurses also reported lower amounts of all challenging behaviors.

Paired samples t-tests were estimated to determine the differences in parent-reported and preoperative nurse-reported challenging behaviors exhibited by the patient preoperatively (see Table 15). Results from these analyses revealed statistically significant differences in self-injurious behaviors, aggressive behaviors, and the total amount of challenging behaviors reported by parents versus preoperative nurses.

PARENTS' STRESS LEVELS

ANCOVAs were used to compare the difference in parents' stress levels between the comparison and intervention groups while controlling for the incidence of language impairment and surgery procedure (see Table 16). No main effects were found among the parents' stress level at arrival to the hospital or parents' total stress level at the hospital between groups; however, parents of children ages 2–5 years old showed significantly lower levels of total stress in the hospital in the intervention group than in the comparison group.

Next, OLS regression analyses were used to predict the parents' total stress level at the hospital using four moderators, separately. To test for moderation, the previously created interaction terms between the focal predictor (i.e., comparison versus intervention

group) and the moderators (e.g., ASPI scores, BPI-S scores, nonverbal diagnosis, and patient age groups) were used. If the interactions were statistically significant, interactions were plotted to interpret the findings. Interactions in which the moderators were continuous variables (e.g., APSI scores and BPI-S scores) were probed and plotted at +/- 1 standard deviation to interpret the findings.

Results from these analyses revealed that parents' ASPI score did not moderate the effectiveness of the intervention for parents' total stress level at the hospital; however, patients' BPI-S score was found to moderate the efficacy of the intervention (see Table 17). After plotting the interactions, results revealed that the parents of children with lower BPI-S scores showed significantly lower levels of stress in the intervention group than parents of children with lower BPI-S scores in the comparison group (see Figure 6). Parents who had children with higher BPI-S scores showed no significant difference in stress level as a function of the intervention.

Parents of patients with a nonverbal diagnosis was found to moderate the efficacy of the intervention for parents' total stress level at the hospital (see Table 18). After plotting the interactions, results revealed that parents of patients who were nonverbal showed marginally higher levels of stress in the comparison and intervention groups than parents of patients who were verbal in the intervention group (referent group; see Figure 7). No significant difference was found in parents' stress level for those who were verbal in the comparison group when compared with those who were verbal in the intervention group. Therefore, the intervention only seemed to be effective for parents of patients who were verbal.

Age groups were found to moderate the efficacy of the intervention for patients' total stress level at the hospital (see Table 19). After plotting the interactions, results from this analysis revealed that parents of children ages 2–5 years old who were in intervention

group showed significantly lower levels of stress than parents of children ages 2–5 years who were in the comparison group (referent group; see Figure 8). Parents of patients 13 years of age and older who were in the comparison and intervention groups showed significantly lower levels of stress than parents of patients ages 2–5 who were in the comparison group. No significant differences were revealed among parents' stress levels at the hospital who had children ages 6–12 years old as a function of the intervention. Therefore, the intervention seemed to be most effective for parents of patients ages 2–5 years old; however, parents of patients ages 13 years and older seemed to report low stress levels at the hospital regardless of their intervention status.

NURSING STAFF'S STRESS LEVELS

ANCOVAs were used to compare the difference in nursing staff's stress levels between the comparison and intervention groups while controlling for the incidence of language impairment, surgery procedure, and recovery room nurses' stress level on a typical day (see Table 20). No significant differences in stress level were revealed among the groups of nursing staff as a function of the intervention.

Next, OLS regression analyses were used to predict each group of nursing staff's (preoperative, operating room, recovery room, and post-operative discharge nurses) stress levels when caring for patients using four moderators, separately. To test for moderation, the previously created interaction terms between the focal predictor (i.e., comparison versus intervention group) and the moderators (e.g., ASPI scores, BPI-S scores, nonverbal diagnosis, and patient age groups) were used. If the interactions were statistically significant, interactions were plotted to interpret the findings. Interactions in which the moderators were continuous variables (e.g., APSI scores and BPI-S scores) were probed and plotted at +/- 1 standard deviation to interpret the findings.

Parents' APSI scores were found to moderate the efficacy of the intervention for operating room nurses' stress level (see Table 21). After plotting the interactions, results from this analysis revealed that when caring for patients of parents who reported lower APSI scores the stress level of operating room nurses was significantly lower in the intervention group than in the comparison group (see Figure 9). There was no significant interaction found when caring for patients whose parents reported higher APSI scores for operating room nurses' stress levels as a function of the intervention. Therefore, the intervention was only effective for operating room nurses who cared for patients whose parents reported lower APSI scores (lower levels of stress regarding their child's ASD diagnosis on a regular basis). Parents' APSI scores were not found to moderate the efficacy of the intervention for the other three nursing groups.

Patients' BPI-S scores were not found to moderate the efficacy of the intervention for any of the four nursing groups. Also, patients with a nonverbal diagnosis were not found to moderate the efficacy of the intervention for any of the four nursing groups.

Age groups were found to moderate the efficacy of the intervention for post-operative discharge nurses' stress level (see Table 22). After plotting the interactions, results from this analysis revealed that post-operative discharge nurses who cared for patients ages 13 years and older in the intervention group reported marginally higher levels of stress than those who cared for patients in the comparison group who were 6–12 years of age (referent group; see Figure 10). No additional significant interactions were found in this model. Therefore, the intervention did not seem to be effective for post-operative discharge nurses' stress level when caring for patients who were 13 years and older. Age groups were not found to moderate the efficacy of the intervention for the other three nurse groups.

Discussion

All children experience stress and anxiety when visiting the hospital (Gaynard et al., 1998; Thompson, 2009; Thompson & Stanford, 1981); however, typical psychosocial interventions (e.g., developmentally appropriate education about an upcoming procedure) that have been known to minimize children's stress and anxiety in the hospital environment may not always be helpful for children with ASD due to the unique challenges of the disorder (Bagshaw, 2011; Scarpinato et al., 2010; Davit et al., 2011; Christiansen & Chambers, 2005). Children with ASD visit the hospital more frequently than their typically developing peers (Venkat et al., 2012; Atladóttir et al., 2012; Scarpinato et al., 2010), so it was imperative to develop a psychosocial intervention program aimed at minimizing the stress levels that children with ASD, and their parents or caregivers, may experience in the outpatient surgery unit, as well as the frequency of challenging behaviors that children with ASD may exhibit in the outpatient surgery unit. In addition, this intervention program aimed to lower the stress levels of nursing staff who cared for children with ASD, and to provide education for nursing staff about the ASD diagnosis and possible accommodations that could be made to the medical environment to assist in minimizing stress for this patient population.

There were several key findings in this research study. First, preoperative and operating room nursing staff were found to provide significantly more accommodations for those patients in the intervention group than for patients in the comparison group. This provides evidence that nursing staff reported a change in their practice for those patients and families in the intervention group and thus partially confirms fidelity of the intervention. Next, the intervention program was shown to be effective at lowering the stress levels for (1) parents of children ages 2–5 years old, (2) patients (and the parents of children) with lower levels of challenging behavior reported on a daily basis, (3) patients

(and the parents of patients) who were verbal, and (4) patients ages 6–12 years old. Third, promising results were found when analyzing the amount of challenging behaviors exhibited by the patients, specifically for the preoperative and post-operative discharge nursing groups. Lastly, the intervention was effective at lowering operating room nurses' stress level when caring for patients and their parents who reported lower parenting stress on a daily basis. All findings will be discussed in depth in the subsequent sections.

STUDY IMPLEMENTATION

This study was successfully implemented for two key factors. First, this study was built around the daily tasks that nursing staff typically encounter in the outpatient surgery unit so that implementing the intervention program would not be a burden for nursing staff. Second, this psychosocial intervention program was developed by parent advisors and multidisciplinary medical staff on the outpatient surgery unit PFCC committee and founded on the core concepts of PFCC.

Study Feasibility

One of the reasons this study was successful was because it was implemented by clinical staff in a clinical setting. The study was built around the daily tasks that nursing staff and additional medical team members (i.e., anesthesia team) usually encounter so that it would not be a burden for medical staff to implement. Nursing staff were able to successfully implement the intervention program as evidenced by the preoperative and operating room nurses' report of providing significantly more accommodations for patients and families in the intervention group than the comparison group, and post-operative discharge nurses' report of providing marginally more accommodations for patients and families in the intervention group than the comparison group. This shows that the nursing groups, except recovery room nurses, seemed to follow through with the

accommodations requested on patients' individualized coping plans for the intervention group. Recovery room nurses may have not had much leeway in accommodations that could be made for patients and families due to the critical care needed for patients when waking up from general anesthesia. (Recovery room nurses have to closely monitor the patients' airway, vital signs, and pain levels, and must be ready in the case of an emergency airway issue).

This study demonstrated great external validity because it was practical and could be easily generalized to outpatient surgery centers within a hospital environment or a free-standing outpatient surgery clinic for both pediatric and adult patients. In fact, the research team was asked to adapt and implement the intervention program in the emergency department and inpatient units at the pediatric hospital by the study site's hospital administration team. Thus, hospital staff seemed to think that this intervention could be easily implemented in similar healthcare settings.

One of the tradeoffs made for the feasibility of the study was that of low internal validity. For this intervention program, it was not possible to complete a randomized controlled trial without largely disrupting the job duties and flow of nursing staff. (Frankly, a randomized controlled trial would probably not have received approval from outpatient surgery management due to this disruption). A randomized controlled trial would have required randomizing nursing staff to control and intervention groups—meaning only half of the nurses would attend the educational session on caring for patients with ASD. To make the study work, nurses from both the control and intervention groups would have to be present each day. This was not compatible for the varied schedules of nursing staff. Nursing staff typically worked four 10 hour shifts per week or three 12 hour shifts per week in the outpatient surgery unit. Therefore, nurses would have to be assigned to study conditions based on their work schedules and having

an equal number of nurses in the control and intervention groups on any given day. This already discounts the random assignment to study conditions. However, the most severe disruption would occur during the normal flow of nurse assignment to patients on a daily basis. The nursing staff at this facility took care of an average of 50 patients per day, and occasionally there was a patient with ASD to be enrolled in the study. Nurses would not be able to wait to care for a study participant, but would need to care for the next patient on the schedule (regardless of ASD diagnosis or not). It could have been possible that there would not have been a match in groups with nursing staff participants and patient participants at any given time. This could have led to nursing staff non-compliance when assigned to patients in the study. Thus, the randomized controlled trial would not have made the intervention program feasible in the outpatient surgery unit. Therefore, it was determined to collect data on a comparison group of patients with ASD prior to providing the intervention education session to all nursing staff during the departmental staff meetings, and then collect data on the intervention group.

To address the internal validity of the study, the comparison and intervention groups were tested to determine if they were matching in patient and parent/legal guardian characteristics. Overall, the groups seemed to match well. The BPI-S and APSI provided an understanding of the patients' and parents' daily functioning and stressors, and no significant differences were found between groups. Only two differences were revealed between groups: (1) parent-reported diagnosis of language impairment and (2) amount of surgery procedures performed. Parents reported language impairment more frequently in the comparison group than the intervention group. This could mean that the comparison group was more severe on the autism spectrum than the intervention group; however, there was a flaw related to parent-reported diagnoses. Parents were asked about their child's medical history one or several days prior to their child's procedure by a

nurse over the phone. Parents had to voluntarily report the medical history of their child. It is known that the diagnosis of language impairment has been inconsistently reported in the literature on children with ASD because some people assume that the language impairment diagnosis is lumped into the ASD diagnosis (Conti-Ramsden et al., 2006; Loucas et al., 2008). Therefore, this difference may not be accurate. However, assuming there was a significant difference between groups, language impairment was used as a covariate for all models. Also, the intervention group patient participants underwent surgery procedures more frequently than the comparison group so surgery procedure was also used as a covariate for all models.

The nursing group stress levels on a typical day at work and on a stressful day at work were mostly matching, except recovery room nurses reported significantly higher stress levels on a typical day when caring for patients in the intervention group. This could be due to the time of year in which data were collected for both groups. Comparison group data were collected in the summer months whereas intervention group data were collected from the months of January through October. The beginning of a year may coincide with changes to clinical practice, which could increase nurses' stress level. Recovery room nurses' stress level on a typical day was used as a covariate for all relevant models.

Patient- and Family-Centered Care Healthcare Delivery Model

Another reason the psychosocial intervention program was successfully implemented in the pediatric outpatient surgery unit was because it was developed by parent advisors and multidisciplinary medical staff on the outpatient surgery PFCC committee. The psychosocial intervention was founded on the core concepts of family-centered care, and viewed parents and legal guardians as the expert on their child—

understanding that parents or caregivers know the specific challenges for their child's ASD symptoms and how to best help their child in a stressful setting.

One unique aspect of this research study was that its development and implementation was also based on the core concepts of PFCC. A family advisor was on the research team and took part in the entire research process. She even helped with data collection! This was a novel approach to research in the healthcare field, and the research team went to the International Institute of Patient- and Family-Centered Care Conference in 2014 to discuss how they were able to implement a research study with a family advisor on the team. Additional family advisors participated in measure development and completed each measure to make sure they were appropriate and a reasonable length for parents to complete. (Some parents of children with ASD did not receive respite care so the time when their child was under general anesthesia was their only respite time and they probably did not want to spend it answering surveys for the study).

PARENTS' AND PATIENTS' STRESS LEVELS

Main Effects

No main effects were found between groups for patients' and parents' stress level at arrival to the hospital or patients' and parents' total stress levels at the hospital; however, after dividing the sample into three age groups (ages 2–5, ages 6–12, and age 13 and older), there was one significant effect for parents' total stress level at the hospital and one marginal effect for patients' total stress level at the hospital. The intervention was significantly effective at lowering *parents'* total stress level at the hospital when parents had children ages 2–5 years old. Parents of young children with ASD would have the most recent ASD diagnosis when compared with parents of older children with ASD and would experience high levels of stress due to the adaptation of having a child

diagnosed with a developmental disorder. Parents of younger children with ASD may have also been more inclined to feel stressed about their child's upcoming procedure with general anesthesia because they have not had as many healthcare experiences with their child when compared with parents of older children. This parent population may have also felt stressed about the unknown experiences in the outpatient surgery unit. Therefore, this intervention seemed to be more effective for parents of younger children because some of the unknown elements (e.g., using a mask for anesthesia induction versus an injection) were eliminated after talking with a child life specialist on the phone the day prior to the procedure and making an individualized coping plan for their child's procedure. Parents of younger children with ASD may have also benefitted from learning that the hospital was completing research to improve the care for children with ASD because this may have provided a sense of normalization by acknowledging that other children have ASD and other parents are feeling similar levels of stress. However, this brings up the question as to whether this main effect would be found if the intervention program were to be implemented with a group of typically developing children, ages 2–5, and their parents. Would all parents of younger children benefit from this psychosocial intervention program regardless if their child has ASD or not? This will be discussed further in the future implications section.

The intervention was marginally effective at lowering *patients'* total stress level at the hospital when children were ages 6–12 years old. Middle childhood is characterized by increased reasoning and logic (Lightfoot, Cole, & Cole, 2013), and it is likely that this age group was able to understand the reason behind having a procedure with general anesthesia. It is likely that this age group of children benefitted from understanding the steps they were to follow when they arrived at the hospital for their procedure on the following day. Also, knowing the steps at least one day prior to their procedure would

have allowed them to start coping with the change of routine the night before the procedure and ease the transition to the hospital environment that would happen on the following day.

This intervention program promoted problem-focused coping (manage or change the situation to handle the stressor), but there may have been an unexpected emotion-focused coping component as well. Because parents and children knew the coping plan the night before, this may have provided the necessary time for children to express, process through, and then regulate their emotional responses for the next day. In short, this intervention program could have provided the time necessary for the child to be angry or anxious at home about the upcoming procedure and then allow the child to focus on managing the stressful situation (i.e., outpatient surgery procedure) to successfully cope through the procedure day on the day of the procedure. Because middle childhood is characterized by logic and reasoning (Lightfoot et al., 2013), this developmental level seems especially capable of actively participating in their own problem-focused coping techniques. However, with this explanation, the same effects in children ages 6–12 years old would be expected for the adolescent age group (13 years and older) and this is not the case. Goldberger and colleagues (2009) reported that an individual's coping can be influenced by their previous experiences. One explanation to consider is the adolescent age group's amount of exposure to the medical environment. It is assumed that adolescents have spent more time at doctor's offices or hospitals than younger children. It is known that children with ASD are more likely to experience a traumatic experience at a medical appointment when compared with typically developing children (Bagshaw, 2011; Scarpinato et al., 2010; Davit et al., 2011; Christiansen & Chambers, 2005). In addition, children with ASD visit doctors' offices and hospitals more frequently than typically developing children (Venkat et al., 2012; Atladóttir et al., 2012; Scarpinato et

al., 2010). Therefore, it can be assumed that adolescents, ages 13 years and older, have spent more time in contact with the medical environment and potentially had more traumatic medical experiences than younger children. Perhaps this history of medical experiences, and the potential for repeated traumatic medical experiences, makes it so that the effects of the intervention program are not seen after one atraumatic medical experience. Instead, this age group may need to experience repeated positive or atraumatic medical experiences in order for any main effects to be seen.

There are several possibilities as to why minimal main effects were revealed between groups for patients' and parents' stress levels at the hospital. First, there may have been diffusion among the groups. Second, child life specialist services were considered part of the standard of care for the comparison group and may have been able to accomplish the same effects as the intervention program. Third, the implementation of individualized coping plans may have been disrupted.

One of the reasons main effects were not seen between groups for patients' and parents' stress levels could have been due to diffusion of the intervention among groups. Because of the PFCC committee's increased focus on minimizing stress for patients with ASD and their parents, child life specialists and other members of the outpatient surgery PFCC committee had started increasingly advocating for patients with ASD to receive special accommodations prior to comparison group data collection. Thus, nurses and some multidisciplinary staff could have already changed the way they cared for patients with ASD before comparison group data collection occurred. Thus, there was not much change actually occurring in between the comparison and intervention group data collection.

In addition, by tracking the amount of accommodations made for patients in both groups, all nurses had a checklist of accommodations to review when caring for the

patient (see Appendix C), meaning that having the information (e.g., viewing "no hospital gown change" on the checklist) could have given the nurse an idea to make that accommodation for the patient (e.g., not make the patient change into a hospital gown before going to the operating room). However, this does not account for the significant difference in accommodations reported between groups by preoperative and operating room nurses unless nursing staff over-reported the accommodations made for their patients in the intervention group due to expectancy bias.

Another reason main effects for patients' and parents' stress levels may not have been seen between groups was because child life specialist services were considered part of the standard of care for the comparison group. The typical standard of care for child life specialists were to highly prioritize patients with ASD in the outpatient surgery unit due to the unique challenges this population may experience in the medical environment. Therefore, most patients in the comparison group would have received child life services throughout their experience in the outpatient surgery unit. The intervention program was a more extensive child life specialist intervention (i.e., phone call the day prior to the procedure), but child life specialists could have been able to accomplish the same intervention on the day of the procedure.

It was also possible that the medical team was not able to fully implement the individualized coping plans due to a variety reasons. For instance, there could have been an emergency at the hospital causing a delay in the surgery schedule. Because patients must fast at least eight hours prior to anesthesia induction, increasing the preoperative wait time for patients could have led to frustration and challenging behavior. This unexpected wait time could have washed out any of the effects of initially successful coping plans.

Subgroup Effects

Although there were no significant main effects for patients' total stress levels at the hospital between the groups, there were additional subgroups in which the intervention group seemed to have lower stress levels than the comparison group. First, patients and parents of patients with a lower BPI-S score (e.g., patients with lower amounts of challenging behavior exhibited at home on a daily basis) showed a significantly lower stress level at the hospital in the intervention group than the comparison group. Because children with more severe challenging behaviors (e.g., children with higher BPI-S scores) are known to have more severe symptoms of ASD (Jang et al., 2011), it was expected that children with lower BPI-S scores were less severe on the autism spectrum and able to communicate and function more independently than those with severe ASD symptoms. Therefore, this intervention was most helpful at lowering the stress levels for children who could understand the need for having the procedure with general anesthesia and benefit from understanding what will happen ahead of time when transitioning to a new place (e.g., hospital). The intervention included at least one night for the parent and patient to emotionally and cognitively process the coping plan for the next day's procedure versus those in the comparison group who may have created an individualized coping plan with their parent and child life specialist immediately prior to their procedure (sometimes less than 30 minutes prior to their procedure start time).

The next subgroup that seemed to benefit from the intervention program were patients and parents of patients who were verbal. Patients' and parents' total stress level at the hospital were marginally lower for those who were verbal in the intervention group compared with those who were nonverbal in the comparison and intervention groups. Those who were verbal were better able to express their concerns about the upcoming

procedure to their parents and identify accommodations that could be made at least one day before the procedure compared with those patients who were nonverbal and unable to verbalize their feelings or concerns. Similar to the previous idea presented, children who were verbal had less severe ASD symptoms and less challenges than those children who were nonverbal. Therefore, children who were verbal were better able to understand the reason for having to go to the hospital and able to convey their concerns about the upcoming procedure to their parent, who was then able to create an individualized plan to help the patient manage the specific stressors related to the patient.

INCIDENCE OF CHALLENGING BEHAVIOR

There were no main effects between groups revealed in parents' ratings of challenging behavior exhibited by the patient, but there were marginally lower levels of aggressive behavior reported by the preoperative and post-operative discharge nurses. In fact, over half of the means of nurse-reported challenging behaviors were lower for the intervention group—just not enough to show a statistically significant difference between groups. This was a promising result. The sample size for this intervention could have been too small and thus there was not enough power to detect differences between groups.

Interestingly, there were no significant correlations documented among parent- and nurse-reported challenging behaviors. In fact, there were statistically significant differences in the amount of challenging behavior reported by the parent when compared with the amount of challenging behavior reported by the preoperative nurse. Parents rated that their children exhibited more challenging behaviors than the preoperative nurses rated. This could be because the parent remained in the preoperative room with the patient for the entire wait time before the procedure whereas the preoperative nurse left the patient's room when their check-in was complete, and therefore was not able to

observe all of the behaviors exhibited by the patient. This could also be because the preoperative nurse may have been focused more on the patient's information in the chart versus observing the patient. Or, nurses may only report certain behaviors that are concerning to them (i.e., self-injurious or aggressive behaviors) whereas parents may report all of their child's behaviors. In addition, parents were familiar with the challenging behaviors their child exhibited at home and may have been more likely to rate that their child exhibited those behaviors preoperatively even if they did not.

Another reason there may not have been a significant difference in the display of challenging behavior is because children with ASD may use repetitive, stereotyped behaviors as a coping mechanism. In fact, some of the individualized coping plans (in the section "Coping Skills/Likes") included the child's stereotyped behavior (e.g., twirling beads) because the parent had reported it was comforting to her child. In the future, these behaviors may need to be categorized and analyzed as coping skills.

NURSING STAFF'S STRESS LEVELS

Main Effects

No main effects were seen for the nursing groups' stress levels. There were several reasons considered as to why no main effects were revealed. First, there could have been some expectancy bias for nurses when completing the measure. Next, there was quite a bit of missing data from nursing staff. Last, the educational session for nurses wasn't extensive enough.

There could have been some expectancy bias in that nurses did not want to appear stressed when caring for patients with ASD because that may make them seem like a weaker or less skilled nurse. Some nurses could have rated that their stress was already low when caring for patients with ASD even if they did or did not actually feel that way.

Also, some nurses did not place their completed Staff Stress Survey in the manila folder before passing the folder on to the next nurse. Therefore, the three nurses caring for the patient after the initial preoperative nurse completed the survey could have unintentionally viewed the preoperative nurse's stress rating and this could have skewed their stress ratings or enhanced the expectancy bias.

There was also quite a bit missing data from nursing staff. This could have contributed to the lack of differences seen in the nursing group's stress levels. The reason for missing data was probably due to the fast-paced outpatient surgery unit and then length of the accommodations and challenging behavior checklists. Some nurses only completed the three stress level ratings and accommodations checklist and skipped the challenging behavior checklist. As much as the research team tried to make the study measures not a burden to the nursing staff, the Staff Stress Survey was still an additional form that needed to be filled out—on top of all the mandatory forms that must be completed for nurses' regular job duties. The length of the survey for nursing staff would be something to consider when the intervention is adapted based on the current results.

Nurses' educational intervention may not have been extensive enough or did not provide nurses with the information necessary about patients with ASD to help lower their stress levels. There may need to be more than a 30 minute session on ASD symptoms and possible accommodations to further assist in minimizing the amount of stress nurses experience when caring for children with ASD. The 30 minute session was agreed upon for study feasibility because the sessions took place during the monthly departmental staff meetings. In addition, some nursing groups may have felt they did not need the educational session or the individualized coping plans to assist in minimizing the stressful experiences for patients with ASD and their families.

Subgroup Effects

The intervention was effective for operating room nurses who cared for patients whose parents reported lower levels of stress regarding their child's ASD diagnosis on a regular basis (lower APSI scores). Again, the intervention was effective due to the lower-stressed population (parents with lower APSI scores) when compared with parents who reported higher levels of stress on a regular basis. Parents are known to report higher levels of stress depending on the severity of their child's ASD symptoms (i.e., challenging behaviors; Jang et al., 2011). Therefore, we could consider the parents who reported lower APSI scores had children with lower BPI-S scores. Interestingly, operating nurses' stress level was lowered by the intervention program. Perhaps this is because the intervention was geared toward problem-solving and problem-focused coping and parents who reported lower levels of stress are more adept at using problem-focused coping skills.

The intervention was ineffective for post-operative discharge nurses' stress levels when caring for patients who were 13 years and older. Post-operative discharge nurses' stress levels were higher for patients ages 13 years and older in the intervention group than patients ages 13 years and older in the comparison group. One nurse reported that she became stressed when she knew she was getting a patient with the "green sheet" (the individualized coping plan) because she knew she may have to care for a patient who exhibited challenging behaviors. It is possible that this is one of the reasons why post-operative discharge nurses' stress level was higher for the intervention group, particularly with patients 13 years and older. When considering patients with ASD who may exhibit challenging behavior and who are older, the weight and strength of the patient were brought into consideration by nursing staff and the remainder of the medical team. Caring for older children and adolescents with ASD may have been more stressful for nurses due

to the sheer fact that these children were larger in size and more difficult to physically manage when compared with younger children.

FUTURE IMPLICATIONS

The successful implementation and evaluation of this pilot study brings the healthcare community one step closer to finding a way to help all children with ASD and their parents, as well as the medical staff who care for them. The results from this study will especially help to inform the practice of child life specialists and inspire innovative ideas for psychosocial interventions in the medical setting to be pursued. However, there are several ways that this intervention program and evaluation could be improved upon for future studies.

Intervention Program

This intervention program targeted patients and families who benefit from problem-focused coping techniques. Incidentally, those who seemed to benefit most from this intervention program were those patients who displayed less severe challenging behaviors and less severe symptoms of ASD, as well as their parents. The results from this study inform the healthcare community that perhaps children with more severe challenging behaviors and severe ASD symptoms would benefit from a different type of intervention program. Future studies should look at adapting the current SNAP intervention program to assist those who may benefit from emotion-focused coping techniques. Emotion-focused coping skills may be what is most helpful for children with severe challenging behaviors and severe ASD symptoms because they do not seem to benefit from problem-focused coping techniques. This should be explored further.

A more in depth educational component on children with ASD for nursing staff should be considered prior to replication of this study. An extended educational session

or multiple sessions may be necessary. One of the sessions should include at least one parent of a child with ASD who is willing to explain his experiences at the hospital with his child to medical staff.

Intervention Evaluation

Because this study brought up the fact that the SNAP intervention program may be helpful for typically developing children and their parents, the next evaluation of the intervention group should evaluate the effectiveness of the intervention program for typically developing children and their families. This will parse out what is helpful for all patients and parents and allow the healthcare community to see what is specifically helpful for patients and families of children with ASD.

Due to the amount of missing data from the nursing groups, the Staff Stress Survey should be tweaked so it can be feasibly completed within the time frame nursing staff have to complete the form. Also, some parents skipped the preoperative challenging behavior checklist on the Parent and Caregiver Stress Survey. This checklist may have been too similar to the BPI-S form they also completed at the same time, therefore, it was skipped. The redundancy of the measures should be evaluated. Also, post-intervention surveys should be completed during future studies to further understand the post-operative experiences of patients and families in the intervention program. In addition, it would be beneficial to add measures of the anesthesia team's stress levels and compliance with the accommodations on the individualized coping plans because of their integral role in the intervention program implementation. Measures of child life specialists' stress levels should also be evaluated.

LIMITATIONS

Although one of the strengths of this study was its larger sample size in comparison with other studies of children with ASD undergoing a procedure with general anesthesia, one of the limitations of this study was its small sample size because there may not have been enough power to detect statistically significant differences between groups. In addition, not all nursing staff completed the Staff Stress Survey so there was missing data which contributed to the lack of statistical power. An additional limitation of this study was that there was no measure on the amount of therapies and interventions that children had undergone leading up to their outpatient procedure with general. These data should be gathered to further assess how the comparison and intervention groups matched in patient characteristics, as well as to explore whether a certain type or amount of interventions that occurred outside of the hospital were related to how a child coped during their time in the outpatient surgery unit. Last, another limitation for this study was the tradeoff between study feasibility and internal validity. The possibility of conducting a randomized controlled trial when replicating this study should continue to be evaluated, and innovative ways to implement and evaluate an intervention within an active clinical environment should continue to be cultivated and explored.

CONCLUSION

Children with ASD and their families experience unique challenges when confronted with the medical environment. Medical staff also experience unique challenges when caring for children with ASD and their families. Special considerations and accommodations should be considered for this patient population as well as for the medical staff caring for this patient population. In order to determine the most beneficial accommodations for patients with ASD, their families, and medical staff, more quality

research is needed that incorporates the patient- and family-centered healthcare delivery model and the cognitive theory of stress and coping framework.

Tables and Figures

	Comparison Group		Intervention Group		
	M	*SD*	*M*	*SD*	*t*
Patient information					
Age	9.67	5.65	9.87	4.92	-0.19
Age group: 2–5 years (*n* = 17; *n* = 12)	0.35	0.48	0.25	0.44	1.11
Age group: 6–12 years (*n* = 17; *n* = 25)	0.35	0.48	0.52	0.51	-1.65
Age group: 13 years and older (*n* = 14; *n* = 11)	0.29	0.46	0.23	0.43	0.69
Gender (male)	0.69	0.47	0.81	0.39	-1.41
Parent-reported diagnoses					
Language impairment	0.58	0.50	0.36	0.49	2.10*
Developmental delay	0.36	0.48	0.19	0.40	1.78†
Epilepsy or seizure diagnosis	0.38	0.49	0.21	0.41	1.75†
Anxiety	0.09	0.29	0.13	0.34	-0.56
Patient procedure					
MRI	0.52	0.51	0.38	0.49	1.44
EEG	0.25	0.44	0.10	0.31	1.89†
Dental	0.29	0.46	0.27	0.45	0.23
Surgery	0.23	0.43	0.42	0.50	-1.98*
Parent-reported surveys					
Behavior Problem Inventory-Short	45.68	29.13	40.32	26.42	0.85
Self-injurious behavior	5.22	5.11	5.50	4.69	-0.27
Aggressive behavior	9.68	8.67	8.02	8.18	0.89
Stereotyped behavior	20.00	11.57	15.56	10.48	1.89†
Autism Parenting Stress Index	19.21	10.29	21.89	12.34	-1.15
Patient's stress on a typical day	2.30	1.02	2.26	1.08	0.19

Table 1: Means, Standard Deviations, and Independent Samples T-Tests Between Patient Groups

Note. *n* = 48; *n* = 47 for intervention group parent-reported surveys. † $p < .10$

* $p < .05$.

	Comparison Group		Intervention Group		
	M	*SD*	*M*	*SD*	*t* or X^2
Age	39.14	8.95	40.00	5.87	-0.55
Gender (male)	0.10	0.31	0.15	0.36	-0.65
Caregiver status (parent)	0.06	0.25	0.02	0.15	1.00
Spanish language	0.04	0.20	0.11	0.31	-1.20
Parent-reported stress on a typical day	2.74	1.29	2.37	0.96	1.57
Race/Ethnicity					2.32
White	0.54		0.49		
Hispanic/Latino(a)	0.23		0.34		
Black	0.09		0.11		
Other	0.14		0.06		
Marital status					5.59
Now married	0.59		0.69		
Divorced	0.15		0.21		
Never married	0.15		0.10		
Separated	0.10		0.00		
Education level					1.48
Less than high school graduate	0.05		0.02		
High school graduate or equivalency	0.08		0.12		
Some college, no degree	0.33		0.37		
Associate's degree	0.13		0.07		
Bachelor's degree	0.23		0.24		
Graduate or professional degree	0.18		0.17		

Table 2: Means, Standard Deviations, and Independent Samples T-Tests Between Patient Groups for Parent Characteristics

Note. $n = 48$ for comparison group; $n = 47$ for intervention group.

	Comparison Group		Intervention Group		
	M	*SD*	*M*	*SD*	*t*
Preoperative nurse (*n* = 41)					
Stress level on a typical day	2.06	0.48	2.03	0.69	0.22
Stress level on a stressful day	3.49	0.78	3.25	1.06	1.16
Operating room nurse (*n* = 33)					
Stress level on a typical day	2.27	0.84	2.50	0.76	-1.18
Stress level on a stressful day	3.38	0.90	3.78	1.04	0.24
Recovery room nurse (*n* = 34)					
Stress level on a typical day	1.86	0.84	2.49	0.96	-3.10**
Stress level on a stressful day	3.33	1.12	3.68	1.29	-1.26
Post-operative discharge nurse (*n* = 31)					
Stress level on a typical day	2.06	0.70	2.23	0.60	-1.03
Stress level on a stressful day	3.45	0.79	3.56	0.73	-0.57

Table 3: Means, Standard Deviations, and Independent Samples T-Tests Between Patient Groups for Nurse Characteristics

Note. ** $p < .01$.

Stress Levels	1	2	3	4	5	6	7	8	9	10
1. Patient: Hospital arrival	-									
2. Patient: Total at hospital	.65***	-								
3. Patient: Typical day	.33*	.18	-							
4. Parent: Hospital arrival	.60***	.54***	.07	-						
5. Parent: Total at hospital	.41**	.62***	.01	.71***	-					
6. Parent: Typical day	.01	-.07	.69***	.00	.02	-				
7. Preoperative nurse	.40**	.39**	-.10	.21	.15	-.21	-			
8. Operating room nurse	.06	.15	-.35*	.15	.19	-.17	.05	-		
9. Recovery room nurse	-.04	.17	.01	.23	.19	.06	.21	.36*	-	
10. Post-operative discharge nurse	.18	.17	-.01	.30†	.14	-.11	.32†	-.05	.23	-

Table 4: Correlation Matrix for Comparison Group Patient, Parent, and Nurse Stress Levels

Note. $n = 48$ for patient and parent; $n = 40$ for preoperative nurse; $n = 36$ for operating room nurse; $n = 39$ for recovery room nurse; and $n = 33$ for post-operative discharge nurse. † $p < .10$ * $p < .05$ ** $p < .01$ *** $p < .001$.

Stress Levels	1	2	3	4	5	6	7	8	9	10
1. Patient: Hospital arrival	-									
2. Patient: Total at hospital	.61***	-								
3. Patient: Typical day	.41**	.27†	-							
4. Parent: Hospital arrival	.49***	.41**	.08	-						
5. Parent: Total at hospital	.30*	.57***	.03	.68***	-					
6. Parent: Typical day	.18	.13	.46***	.30*	.24	-				
7. Preoperative nurse	.57***	.22	-.05	.31*	.15	.02	-			
8. Operating room nurse	-.11	.09	.10	-.23	.01	.03	-.05	-		
9. Recovery room nurse	-.03	-.01	.32†	-.08	.21	.13	-.20	.22	-	
10. Post-operative discharge nurse	.39*	.00	.02	.02	-.05	.05	.60***	.03	-.02	-

Table 5: Correlation Matrix for Intervention Group Patient, Parent, and Nurse Stress Levels

Note. $n = 47$ for patient and parent; $n = 43$ for preoperative nurse; $n = 32$ for operating room nurse; $n = 36$ for recovery room nurse; and $n = 32$ for post-operative discharge nurse. † $p < .10$ * $p < .05$ ** $p < .01$ *** $p < .001$.

	1	2	3	4	5	6	7	8
Parent-reported								
1. Self-injurious behavior	-							
2. Aggressive behavior	.75***	-						
3. Stereotyped behavior	.65***	.65***	-					
4. Total behaviors	.87***	.92***	.87***	-				
Nurse-reported								
5. Self-injurious behavior	.13	-.09	.02	.00	-			
6. Aggressive behavior	-.24	.08	.22	.07	.13	-		
7. Stereotyped behavior	-.02	-.18	.04	-.07	.54**	.06	-	
8. Total behaviors	-.06	-.13	.11	-.03	.67***	.36†	.94***	-

Table 6: Correlation Matrix for Parent-Reported and Nurse-Reported Preoperative Behaviors in Comparison Group

Note. $n = 37$ for parent-reported behaviors; $n = 23$ for nurse-reported behaviors. † $p < .10$ ** $p < .01$ *** $p < .001$.

	1	2	3	4	5	6	7	8
Parent-reported								
1. Self-injurious behavior	-							
2. Aggressive behavior	.80***	-						
3. Stereotyped behavior	.69***	.69***	-					
4. Total behaviors	.89***	.92***	.90***	-				
Nurse-reported								
5. Self-injurious behavior	.06	-.04	.35	.15	-			
6. Aggressive behavior	-.18	-.14	-.15	-.18	.08	-		
7. Stereotyped behavior	.25	.26	-.04	.17	-.03	.11	-	
8. Total behaviors	.23	.20	.08	.20	.38†	.26	.91***	-

Table 7: Correlation Matrix for Parent-Reported and Nurse-Reported Preoperative Behaviors in Intervention Group

Note. $n = 42$ for parent-reported behaviors; $n = 24$ for nurse-reported behaviors. † $p < .10$ *** $p < .001$.

	Comparison Group		Intervention Group		
	M	*SE*	*M*	*SE*	*F*
Preoperative nurse (*n* = 39)	1.99	0.39	5.70	0.39	43.96***
Operating room nurse (*n* = 35)	1.89	0.23	3.18	0.26	13.63***
Recovery room nurse (*n* = 37)	1.17	0.23	1.71	0.24	2.67
Post-operative discharge nurse (*n* = 26)	1.06	0.35	1.79	0.31	3.29†

Table 8: Means, Standard Errors, and Analysis of Covariance for Nurse-Reported Accommodations

Note. Adjusted means controlling for language impairment and surgery procedure. † $p < .10$ *** $p < .001$.

	Comparison Group		Intervention Group		
	M	*SE*	*M*	*SE*	*F*
Stress level at arrival to hospital	2.38	0.22	2.39	0.21	0.00
Nonverbal diagnosis (*n* = 13; *n* = 10)	1.86	0.43	2.42	0.52	0.65
Age group: 2–5 years (*n* = 17; *n* = 12)	1.79	0.25	2.03	0.29	0.36
Age group: 6–12 years (*n* = 17; *n* = 25)	2.79	0.37	2.22	0.29	1.38
Age group: 13 years and older (*n* = 14; *n* = 11)	2.77	0.47	3.03	0.57	0.11
Total stress level at hospital	2.97	0.21	2.79	0.20	0.40
Nonverbal diagnosis (*n* = 13; *n* = 10)	2.70	0.44	3.55	0.53	1.44
Age group: 2–5 years (*n* = 17; *n* = 12)	2.64	0.28	2.32	0.32	0.56
Age group: 6–12 years (*n* = 17; *n* = 25)	3.68	0.34	2.81	0.27	4.00†
Age group: 13 years and older (*n* = 14; *n* = 11)	2.67	0.45	3.22	0.55	0.51

Table 9: Means, Standard Errors, and Analysis of Covariance for Patient Stress Levels

Note. *n* = 45 for comparison group; *n* = 46 for intervention group. Adjusted means controlling for language impairment and surgery procedure.

	B (SE)	*β*
Language impairment	0.16 (0.34)	0.06
Procedure: Surgery	0.00 (0.34)	0.00
Intervention status	-1.52 (0.60)	-0.55*
BPI-S score	-0.02 (0.01)	-0.30†
Intervention status * BPI-S score	0.03 (0.01)	0.61**
F	1.67	
df	73	
Adjusted R^2	0.03	

Table 10: Intervention Status Predicting Patients' Total Stress Level at the Hospital as Moderated by BPI-S Score

Note. † $p < .10$ * $p < .05$ ** $p < .01$.

	B (SE)	*β*
Procedure: Surgery	-0.19 (0.30)	-0.07
Intervention status	0.48 (0.32)	0.18
Nonverbal diagnosis (*n* = 13; *n* = 10)	0.86 (0.50)	0.28†
Intervention status * nonverbal diagnosis	-1.21 (0.66)	-0.32†
F	1.15	
df	90	
Adjusted R^2	0.01	

Table 11: Intervention Status Predicting Patients' Total Stress Level at the Hospital as Moderated by Nonverbal Diagnosis

Note. Referent group were patients in the intervention group who were verbal.

† $p < .10$

	B (SE)	*β*
Language impairment	0.29 (0.29)	0.11
Procedure: Surgery	-0.06 (0.30)	-0.02
Intervention status	-0.92 (0.43)	-0.35*
Age group: 2–5 years (*n* = 17; *n* = 12)	-1.07 (0.47)	-0.37*
Age group: 13 years and older (*n* = 14; *n* = 11)	-1.22 (0.49)	-0.40*
Intervention status * age group: 2–5 years	0.54 (0.65)	0.14
Intervention status * age group: 13 years and older	1.86 (0.70)	0.44**
F	1.87†	
df	90	
Adjusted R^2	0.06	

Table 12: Intervention Status Predicting Patients' Total Stress Level at the Hospital as Moderated by Age Groups

Note. Referent group were patients in the comparison group who were 6–12 years of age. † $p < .10$ * $p < .05$ ** $p < .01$.

	Comparison Group		Intervention Group		
	M	*SE*	*M*	*SE*	*F*
Total behaviors	5.89	1.15	5.97	1.04	0.00
Self-injurious behavior	1.13	0.32	1.38	0.29	0.32
Aggressive behavior	2.00	0.48	1.51	0.43	0.58
Stereotyped behavior	2.75	0.48	3.08	0.44	0.25

Table 13: Means, Standard Errors, and Analysis of Covariance for Parent-Reported Preoperative Behaviors

Note. $n = 34$ for comparison group, $n = 41$ for intervention group. Adjusted means controlling for language impairment and surgery procedure.

	Comparison Group		Intervention Group		
	M	*SE*	*M*	*SE*	*F*
Preoperative nurse (*n* = 29)					
Total behaviors	2.93	0.53	1.71	0.58	2.32
Self-injurious behavior	0.17	0.14	0.33	0.15	0.58
Aggressive behavior	0.47	0.14	0.09	0.15	3.52†
Stereotyped behavior	2.28	0.45	1.29	0.49	2.17
Operating room nurse (*n* = 27)					
Total behaviors	1.13	0.33	0.54	0.46	1.05
Self-injurious behavior	0.21	0.07	0.02	0.09	2.65
Aggressive behavior	0.24	0.12	0.11	0.16	0.39
Stereotyped behavior	0.68	0.22	0.41	0.30	0.50
Recovery room nurse (*n* = 30)					
Total behaviors	0.48	0.29	0.90	0.32	0.85
Self-injurious behavior	0.01	0.08	0.11	0.09	0.60
Aggressive behavior	0.15	0.18	0.23	0.21	0.09
Stereotyped behavior	0.28	0.15	0.48	0.17	0.62
Post-operative discharge nurse (*n* = 24)					
Total behaviors	1.26	0.32	0.75	0.34	1.14
Self-injurious behavior	0.04	0.04	0.05	0.05	0.07
Aggressive behavior	0.37	0.13	0.05	0.14	2.96†
Stereotyped behavior	0.85	0.24	0.65	0.26	0.30

Table 14: Means, Standard Errors, and Analysis of Covariance for Nurse-Reported Behaviors

Note. Adjusted means controlling for language impairment and surgery procedure. † $p < .10$.

	Parent-Reported		Nurse-Reported		
	M	*SD*	*M*	*SD*	*t*
Total behaviors	5.17	5.45	2.15	2.85	3.39***
Self-injurious behavior	1.17	1.61	0.24	0.77	3.69***
Aggressive behavior	1.63	2.46	0.30	0.79	3.52***
Stereotyped behavior	2.37	2.28	1.61	2.27	1.59

Table 15: Means, Standard Deviations, and Paired Samples T-Tests for Parent- and Nurse-Reported Preoperative Behaviors

Note. $n = 46$. *** $p < .001$. Groups were combined.

	Comparison Group		Intervention Group		
	M	*SE*	*M*	*SE*	*F*
Stress level at arrival to hospital	2.58	0.19	2.41	0.19	0.41
Nonverbal diagnosis (n = 13; n = 10)	2.16	0.35	2.88	0.42	1.67
Age group: 2–5 years (n = 17; n = 12)	2.92	0.28	2.27	0.32	2.34
Age group: 6–12 years (n = 17; n = 25)	2.55	0.33	2.45	0.26	0.05
Age group: 13 years and older (n = 14; n = 11)	2.43	0.38	2.21	0.46	0.12
Total stress level at hospital	2.60	0.20	2.54	0.19	0.05
Nonverbal diagnosis (n = 13; n = 10)	2.44	0.43	3.31	0.52	1.55
Age group: 2–5 years (n = 17; n = 12)	2.93	0.22	1.93	0.26	8.34**
Age group: 6–12 years (n = 17; n = 25)	2.90	0.36	2.86	0.28	0.01
Age group: 13 years and older (n = 14; n = 11)	2.09	0.37	2.28	0.45	0.09

Table 16: Means, Standard Errors, and Analysis of Covariance for Parent Stress Levels

Note. n = 45 for comparison group; n = 46 for intervention group. Adjusted means controlling for language impairment and surgery procedure.

	B (SE)	*β*
Language impairment	0.67 (0.30)	0.26*
Procedure: Surgery	-0.10 (0.30)	-0.04
Intervention status	-0.84 (0.53)	-0.33
BPI-S score	-0.01 (0.01)	-0.21
Intervention status * BPI-S score	0.02 (0.01)	0.51*
F	2.40*	
df	73	
Adjusted R^2	0.09	

Table 17: Intervention Status Predicting Parents' Total Stress Level at the Hospital as Moderated by BPI-S Score

Note. * $p < .05$

	B (SE)	*β*
Procedure: Surgery	-0.31 (0.29)	-0.11
Intervention status	0.43 (0.31)	0.17
Nonverbal diagnosis (n = 13; n = 10)	0.95 (0.47)	0.32*
Intervention status * nonverbal diagnosis	-1.24 (0.64)	-0.34*
F	1.50	
df	90	
Adjusted R^2	0.02	

Table 18: Intervention Status Predicting Parents' Total Stress Level at the Hospital as Moderated by Nonverbal Diagnosis

Note. Referent group were patients in the intervention group who were verbal.

* $p < .05$.

	B (SE)	*β*
Language impairment	0.60 (0.27)	0.23*
Procedure: Surgery	-0.14 (0.28)	-0.05
Intervention status	-1.06 (0.47)	-0.41*
Age group: 6–12 years (*n* = 17; *n* = 25)	0.01 (0.44)	0.00
Age group: 13 years and older (*n* = 14; *n* = 11)	-1.08 (0.45)	-0.37*
Intervention status * age group: 6–12 years	-0.99 (0.62)	0.34
Intervention status * age group: 13 years and older	1.78 (0.70)	0.43**
F	2.49*	
df	90	
Adjusted R^2	0.10	

Table 19: Intervention Status Predicting Parents' Total Stress Level at the Hospital as Moderated by Age Groups

Note. Referent group were patients in the comparison group who were 2–5 years of age. * $p < .05$ ** $p < .01$.

	Comparison Group		Intervention Group		
	M	*SE*	*M*	*SE*	*F*
Preoperative nurse (*n* = 43)	1.92	0.15	2.18	0.14	1.52
Operating room nurse (*n* = 33)	1.88	0.15	1.87	0.16	0.00
Recovery room nurse (*n* = 36)	2.02	0.14	1.99	0.14	0.02
Post-operative discharge nurse (*n* = 33)	1.84	0.14	1.88	0.14	0.05

Table 20: Means, Standard Errors, and Analysis of Covariance for Nurse-Reported Stress Levels

Note. Adjusted means controlling for language impairment and surgery procedure (and recovery room nurses' stress level on a typical day).

	B (SE)	*β*
Language impairment	-0.14 (0.23)	-0.08
Procedure: Surgery	0.02 (0.25)	0.01
Intervention status	-0.95 (0.48)	-0.56*
APSI score	-0.03 (0.02)	-0.37†
Intervention status * APSI score	0.04 (0.02)	0.77*
F	1.05	
df	63	
Adjusted R^2	0.01	

Table 21: Intervention Status Predicting Operating Room Nurses' Stress Level as Moderated by Parents' APSI Score

Note. † $p < .10$ * $p < .05$.

	B (SE)	*β*
Language impairment	0.00 (0.21)	0.00
Procedure: Surgery	-0.18 (0.22)	-0.11
Intervention status	-0.19 (0.29)	-0.13
Age group: 2–5 years (n = 17; n = 12)	-0.24 (0.36)	-0.13
Age group: 13 years and older (n = 14; n = 11)	-0.24 (0.33)	-0.14
Intervention status * age group: 2–5 years	-0.01 (0.51)	0.00
Intervention status * age group: 13 years and older	0.87 (0.47)	0.37†
F	0.94	
df	63	
Adjusted R^2	-0.01	

Table 22: Intervention Status Predicting Post-Operative Discharge Nurses' Stress Level as Moderated by Age Groups

Note. Referent group were patients in the comparison group who were 6–12 years of age. † $p < .10$.

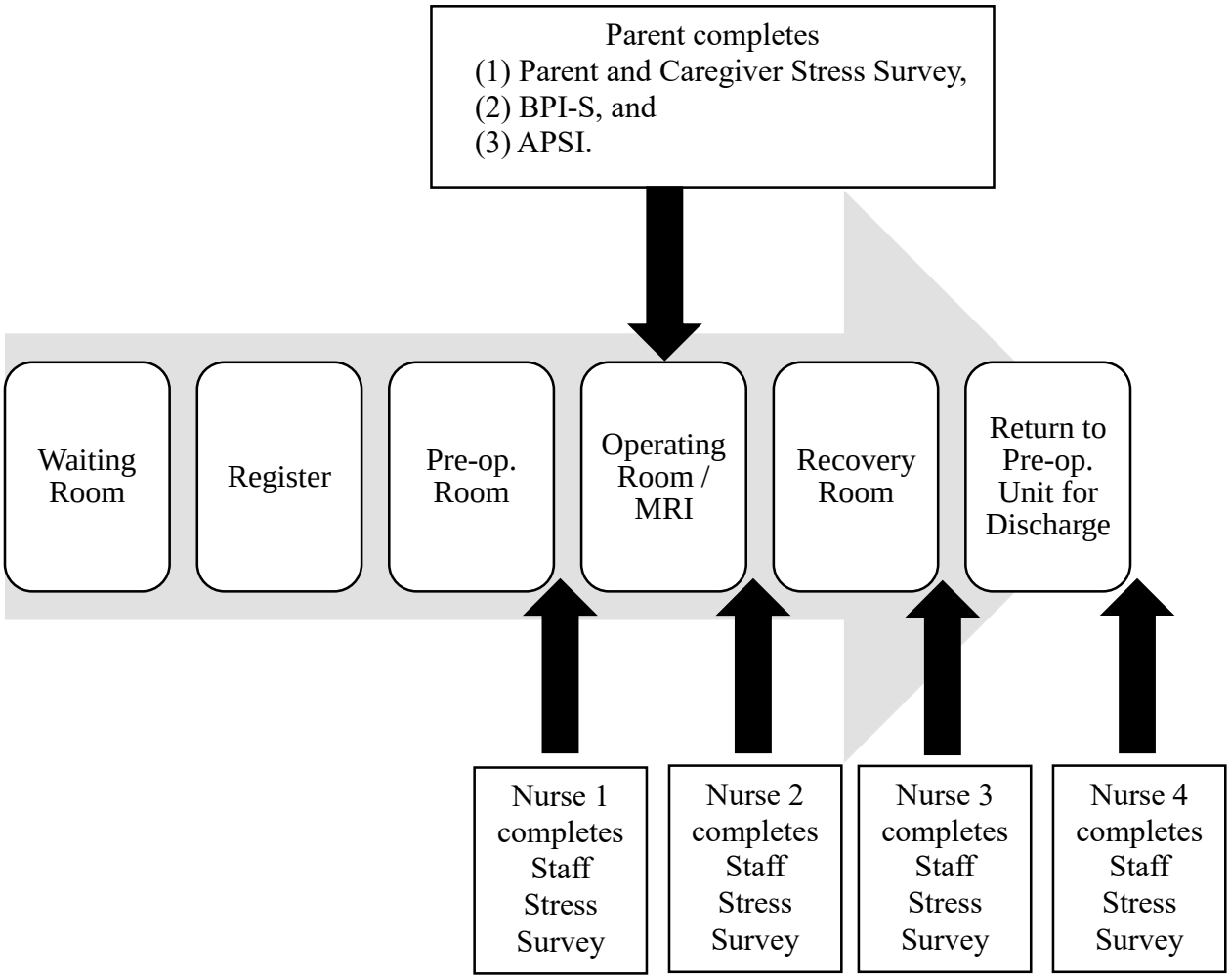


Figure 1: Patient Flow in the Outpatient Surgery Unit with Parent and Nurse Survey Completion Timeline for the Comparison Group

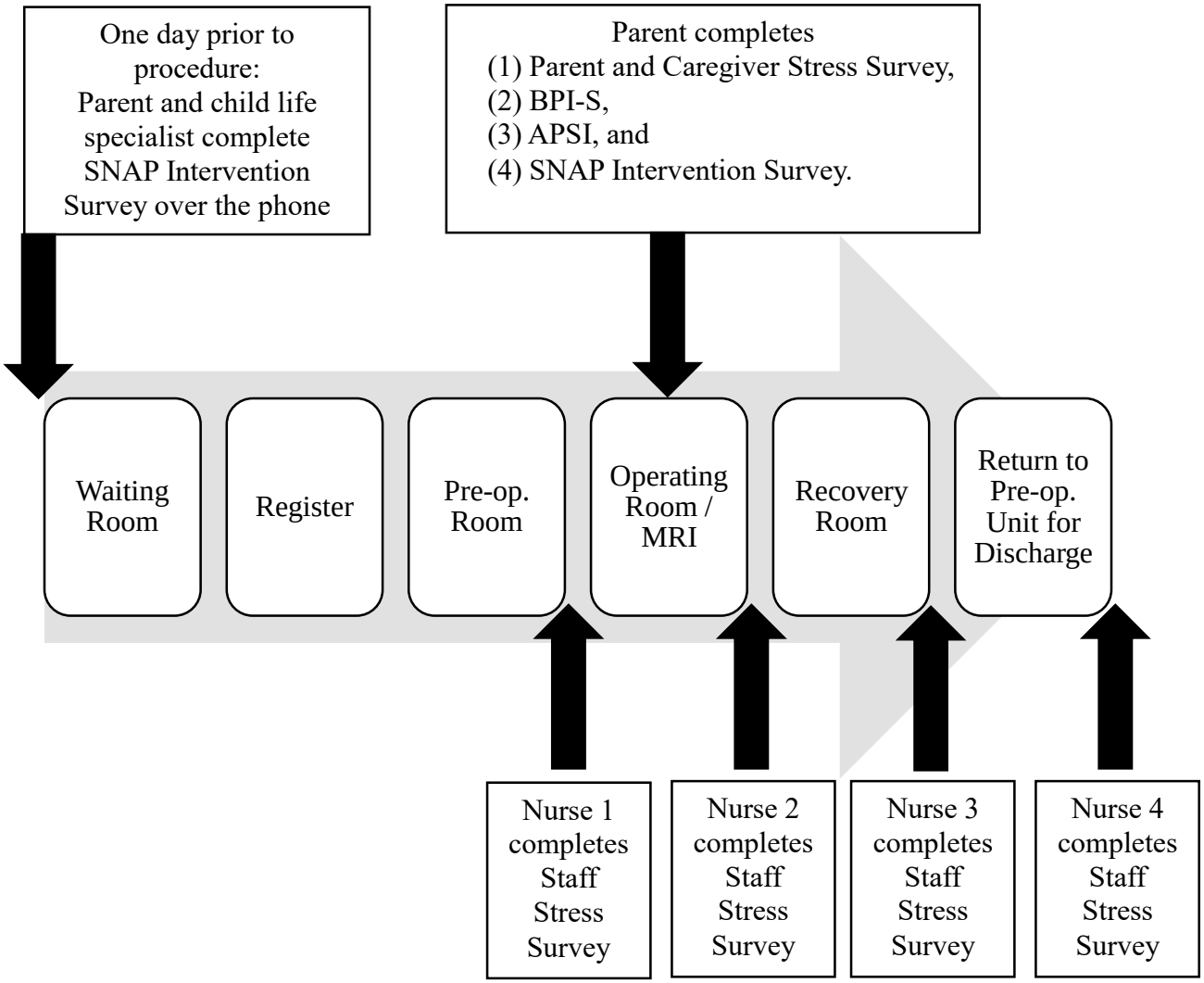


Figure 2: Patient Flow in the Outpatient Surgery Unit with Parent and Nurse Survey Completion Timeline for the Intervention Group

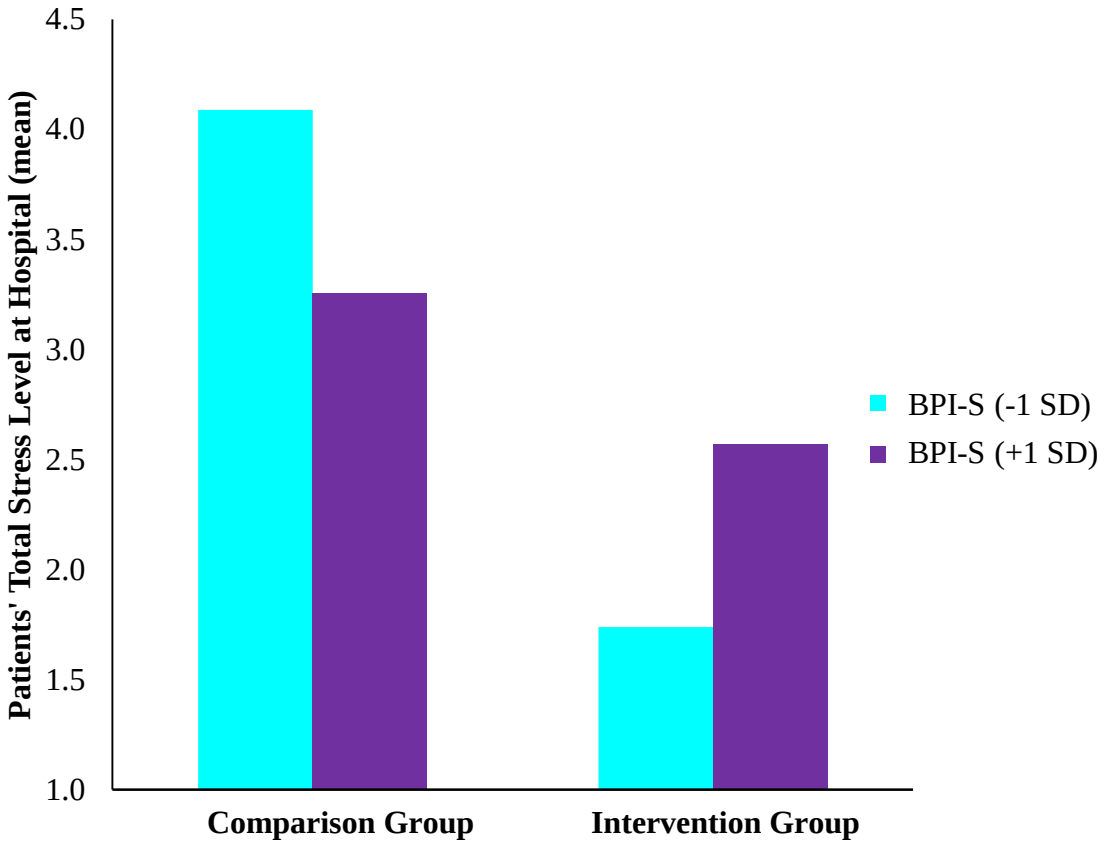


Figure 3: Intervention Status Predicting Patients' Total Stress Level at the Hospital as Moderated by BPI-S Score

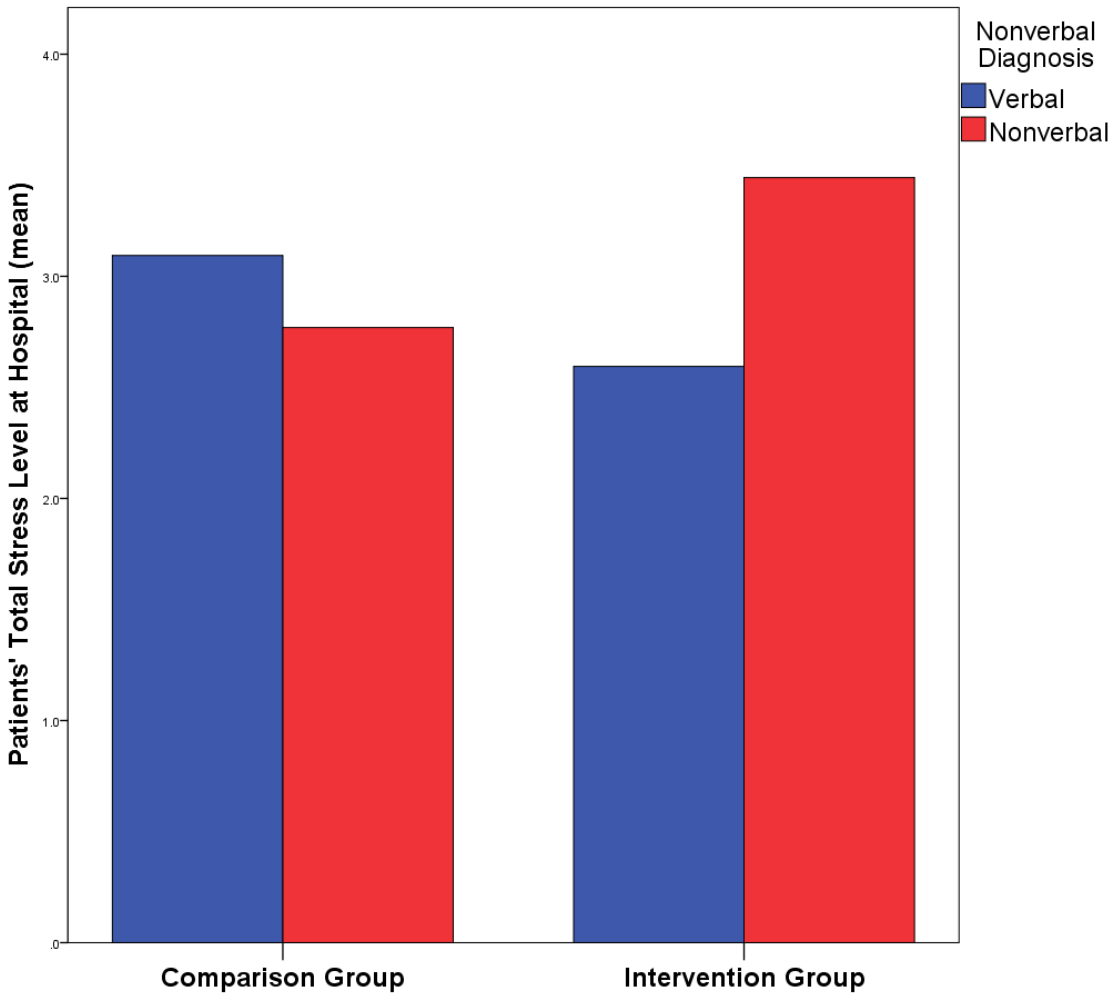


Figure 4: Intervention Status Predicting Patients' Total Stress Level at the Hospital as Moderated by Nonverbal Diagnosis

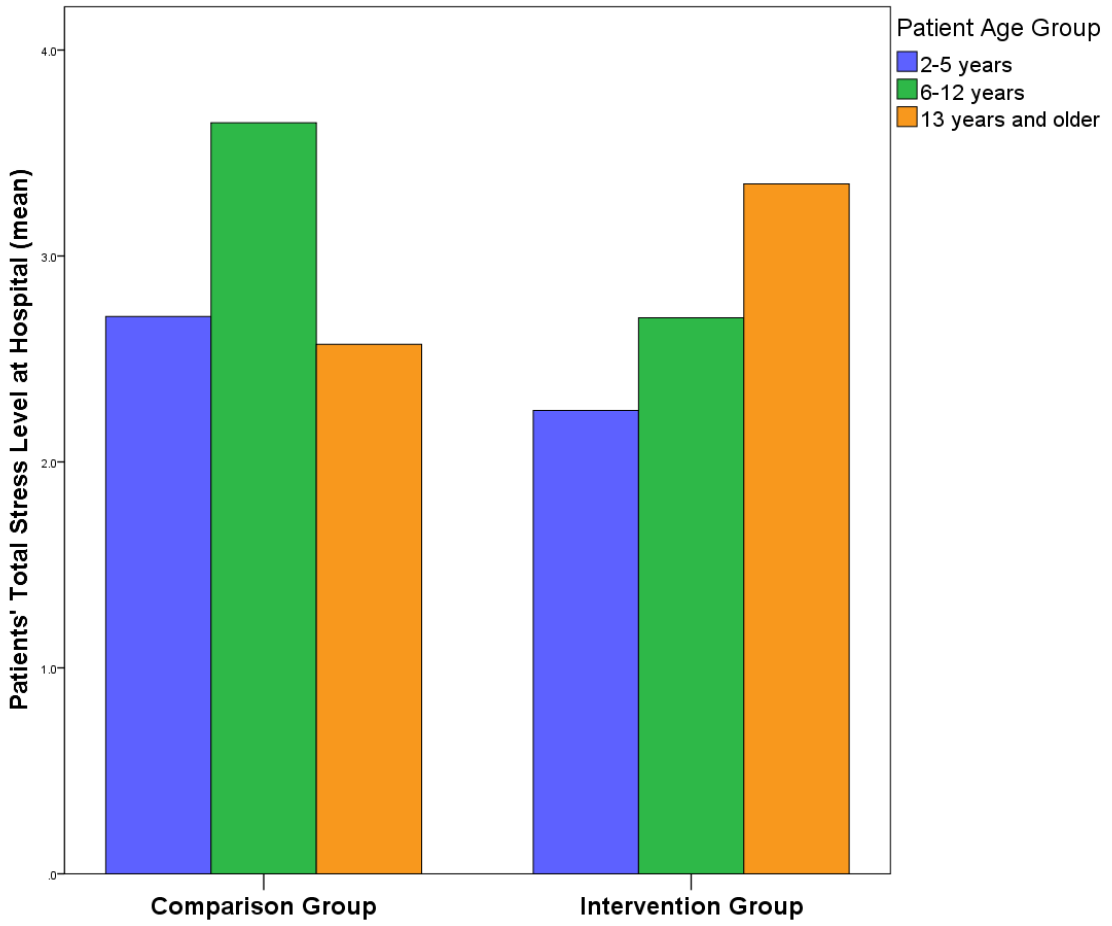


Figure 5: Intervention Status Predicting Patients' Total Stress Level at the Hospital as Moderated by Age Groups

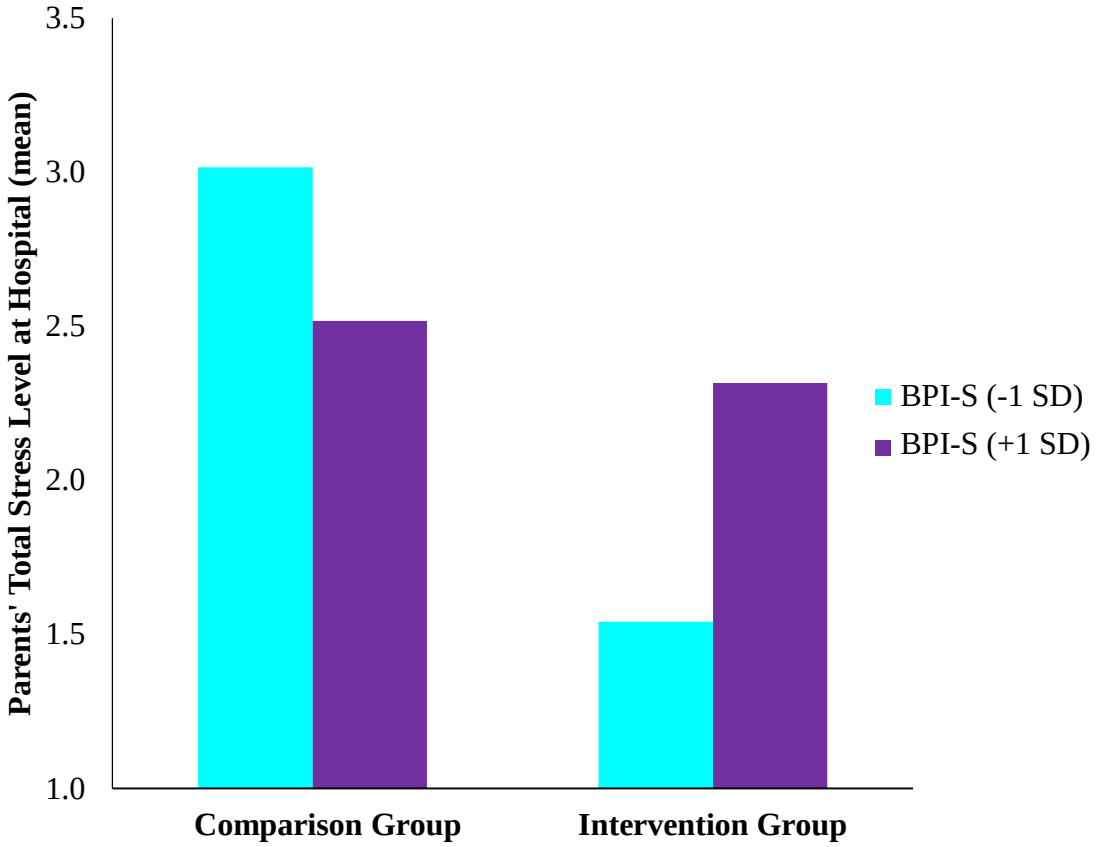


Figure 6: Intervention Status Predicting Parents' Total Stress Level at the Hospital as Moderated by BPI-S Score

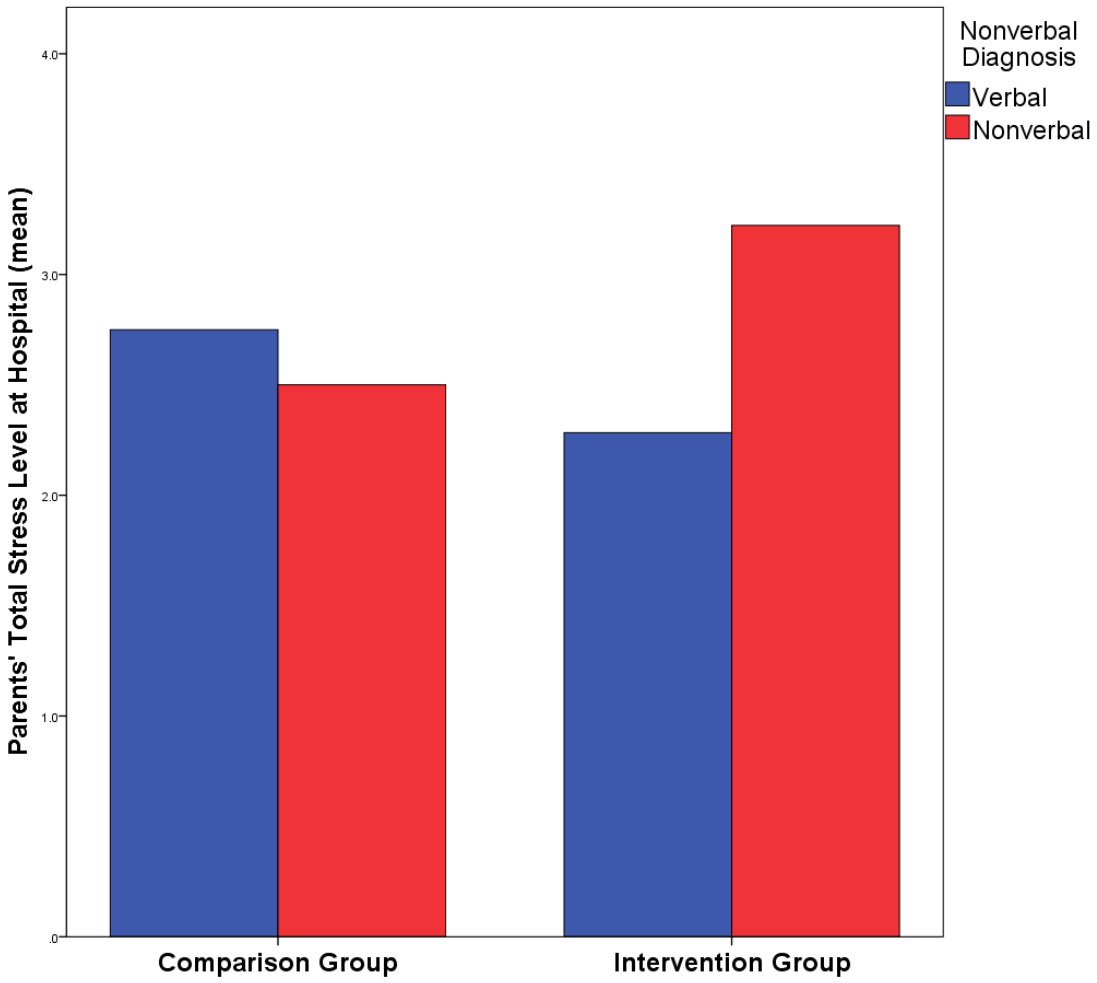


Figure 7: Intervention Status Predicting Parents' Total Stress Level at the Hospital as Moderated by Nonverbal Diagnosis

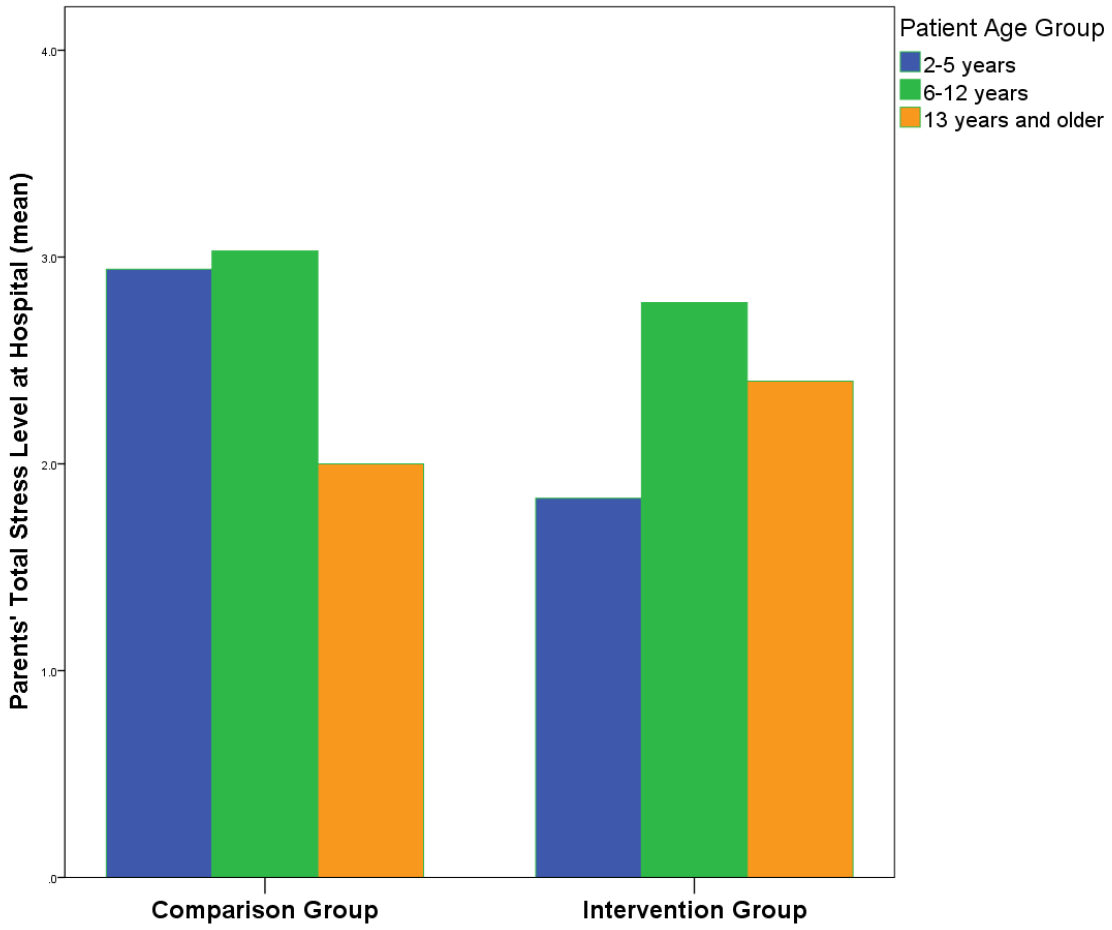


Figure 8: Intervention Status Predicting Parents' Total Stress Level at the Hospital as Moderated by Age Groups

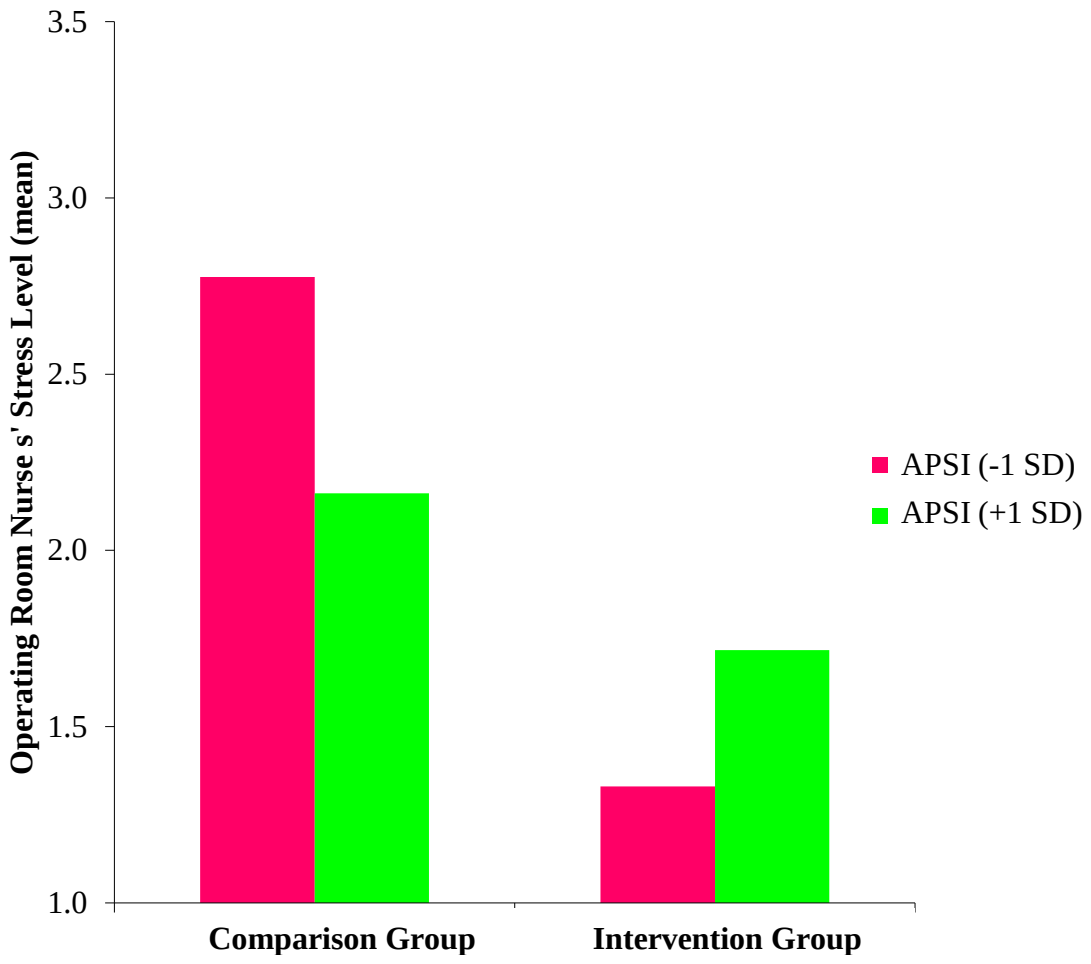


Figure 9: Intervention Status Predicting Operating Room Nurses' Stress Level as Moderated by APSI Score

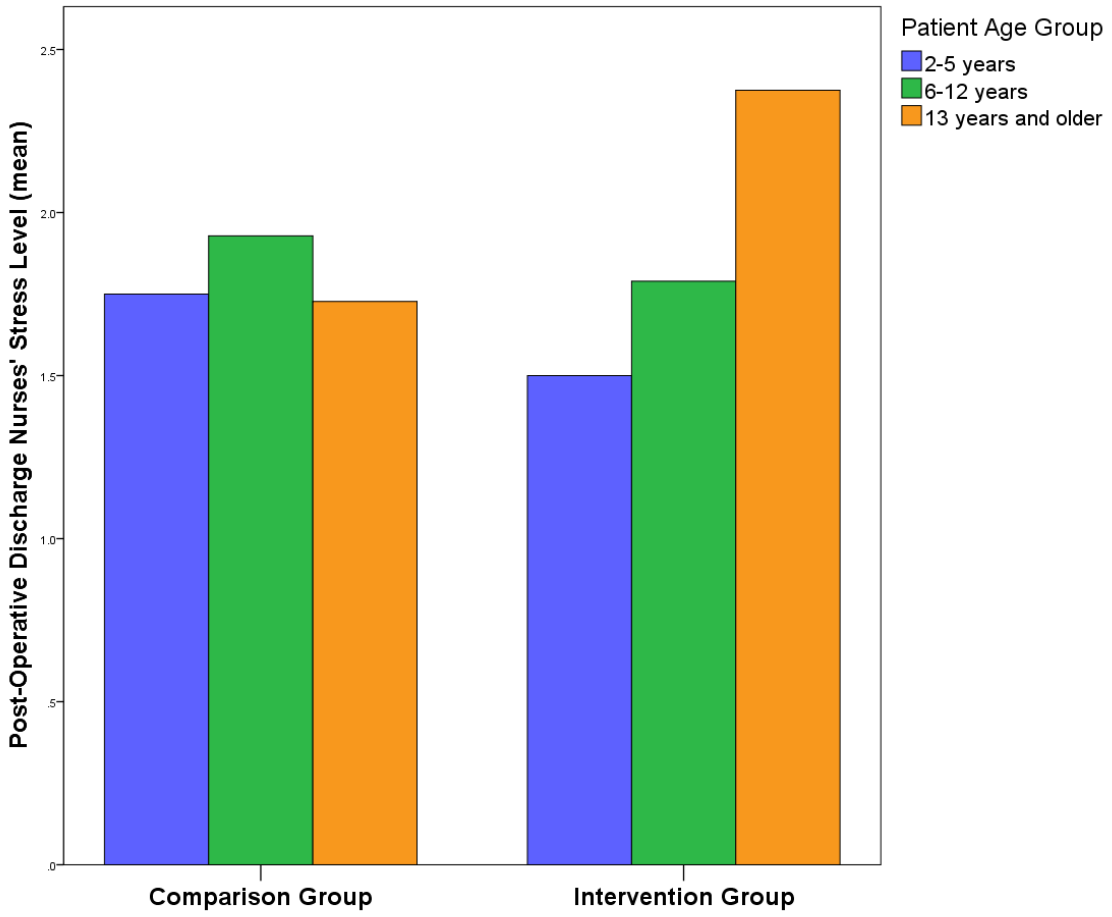


Figure 10: Intervention Status Predicting Post-Operative Discharge Nurses' Stress Level as Moderated by Age Groups

Appendix A

AN OUTLINE OF THE EDUCATIONAL SESSION ON ASD FOR PERIOPERATIVE NURSING STAFF

- Special Needs Assessment and Plan SNAP PILOT STUDY Phase 2: Testing the Intervention
- Outline
    - Briefly review characteristics & symptoms of autism
    - Discuss Phase 2 of the SNAP Pilot Study
- What is autism?
    - Autism spectrum disorder (ASD)
        - Deficits in social communication and interaction
        - Restrictive, repetitive behavior and interests
        - Deficits in Social Communication and Interaction
    - Poor verbal & non-verbal communication
    - Abnormalities in eye contact and body language
    - Deficits in understanding gestures, facial expressions, and body language
    - Difficulty adjusting behavior to different contexts
    - Difficulty understanding and maintaining relationships
    - Difficulty making friends
    - Abnormal social approach
- Restrictive, Repetitive Behavior and Interests
    - Repetitive motor movements, use of objects, or speech
    - Inflexible adherence to routines; insistence on sameness
        - Extreme distress to small change

AN OUTLINE OF THE EDUCATIONAL SESSION ON ASD FOR PERIOPERATIVE NURSING STAFF (CONTINUED)

        - Difficulties with transitions
        - Rigid thinking patterns
    - Highly restrictive, fixated interests that are abnormal in intensity
- Restrictive, Repetitive Behavior and Interests
    - Hyper- or hypo-activity to sensory input
        - Adverse response to sounds or textures
        - Indifference to pain or temperature
    - Unusual interests in sensory aspect of environment
        - Excessive smelling
        - Visual fascination with lights or movement
- It's a spectrum…Severity depends on how much the deficits interfere with daily functioning
- Now imagine how children with autism feel coming to the hospital…
    - What difficulties have you seen in children with autism in the hospital?
        - Lots of sensory input:
        - ID band
        - Hospital pajamas
        - Anesthesia mask and smell
        - Change in routine—which includes being NPO (nothing by mouth)
        - Transitions through department
        - Difficulty understanding staff and communicating
        - Adverse behavior
- All of this, on top of normal pre-op. anxiety and fear that all children experience!

Appendix B

PARENT AND CAREGIVER STRESS SURVEY

- Please circle the number that best fits the stress level.

What was your **child's stress** level when you *arrived* at the hospital?	1 No stress	2	3	4	5 High stress
What was **your stress** level when you *arrived* at the hospital?	1 No stress	2	3	4	5 High stress
What was your **child's total stress** level at the hospital?	1 No stress	2	3	4	5 High stress
What was **your total stress** level at the hospital?	1 No stress	2	3	4	5 High stress
What is your **child's stress** level on a *typical day*?	1 No stress	2	3	4	5 High stress
What is **your stress** level on a *typical day*?	1 No stress	2	3	4	5 High stress

- What did we do well?

- What could we have done better?

PARENT AND CAREGIVER STRESS SURVEY (CONTINUED)

- Did your child show any these behaviors before his or her procedure? Were these behaviors mild, moderate, or severe? Check all that apply.

  Write mild (MI), moderate (MO), or severe (S) next to each behavior listed.

Self-Injurious Behavior	Aggressive and Destructive Behaviors	Stereotyped Behaviors
Self-biting	Hitting others	Rocking, repetitive body movements
Head hitting	Kicking others	Sniffing objects, own body
Body hitting (except for head)	Pushing others	Waving or shaking arms
Self-scratching	Biting others	Manipulating (e.g., spinning) objects
Pica (ingesting non-food items)	Grabbing and pulling others	Repetitive hand or finger movements
Inserting objects in nose, ears	Scratching others	Yelling and screaming
Hair pulling	Pinching others	Pacing, jumping, bouncing, running
Teeth grinding	Verbally abusive with others	Rubbing self
Other:	Destroying things	Gazing at hands or objects
	Bullying–being mean or cruel	Bizarre body postures
	Spitting	Clapping hands
	Other:	Grimacing
		Other:

Adapted from *Behavior Problem Inventory-Short (Rojahn, 2011)*

Appendix C

STAFF STRESS SURVEY

- What is your **stress level** on an *average day* at work?

1	2	3	4	5
Low stress				High stress

- What is your **stress level** on a *stressful day* at work?

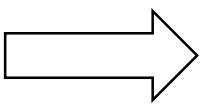
1	2	3	4	5
Low stress				High stress

- What was your **stress level** when working *with this patient*?

1	2	3	4	5
Low stress				High stress

- What accommodations were made for this patient? Check all that apply.

Pre-op.	OR / MRI	Post-op.
Late arrival time	Parental presence for anesthesia induction	Recover in isolation room
Decreased time in waiting room	iPad for diversion during anesthesia induction	Physical location of post-op. bay
Patient Access in pre-op. room	Lighting in OR	Early parental presence in recovery room
Physical location of pre-op. room	Minimize noise in OR	Discharge from recovery room
Lighting in room	Child Life Specialist present	IV removal before patient is awake
Minimize number of staff members		
No vital signs taken upon arrival		
No hospital gown change		
Developmentally appropriate activities/toys provided		
Procedure preparation with Child Life Specialist		
None	None	None



STAFF STRESS SURVEY (CONTINUED)

- What behaviors did the patient exhibit? Check all that apply.

Self-Injurious Behavior	Aggressive and Destructive Behaviors	Stereotyped Behaviors
Self-biting	Hitting others	Rocking, repetitive body movements
Head hitting	Kicking others	Sniffing objects, own body
Body hitting (except for head)	Pushing others	Waving or shaking arms
Self-scratching	Biting others	Manipulating (e.g., spinning) objects
Pica (ingesting non-food items)	Grabbing and pulling others	Repetitive hand or finger movements
Inserting objects in nose, ears	Scratching others	Yelling and screaming
Hair pulling	Pinching others	Pacing, jumping, bouncing, running
Teeth grinding	Verbally abusive with others	Rubbing self
Other:	Destroying things	Gazing at hands or objects
	Bullying–being mean or cruel	Bizarre body postures
	Spitting	Clapping hands
	Other:	Grimacing
		Other:
None	None	None

Adapted from *Behavior Problem Inventory-Short Form (Rojahn et al., 2012).*

Appendix D

SPECIAL NEEDS ASSESSMENT AND PLAN (SNAP) INTERVENTION SURVEY

Patient/Family Demographics:

Number of people in household: _____

Age(s) of sibling(s): _____

Do any of your other children have autism spectrum disorder? Yes No

Parent/Caregiver Birth Year: _____

Parent/Caregiver Marital Status:	Parent/Caregiver Education Level:
Divorced	Less than high school graduate
Never married	High school graduate (includes equivalency)
Now married/domestic partner	Some college, no degree
Separated	Associate's degree
Widowed	Bachelor's degree
	Graduate or professional degree

Patient Assessment:

1. **Does your child have an autism spectrum disorder, intellectual disability, or challenging behaviors?** Yes No

2. **Does your child get nervous or stressed at doctor or dentist appointments or in the hospital?** Yes No
   a. **If yes,** was there a specific experience that severely frightened or stressed your child? Please describe.

SNAP INTERVENTION SURVEY (CONTINUED)

3. What triggers your child's stress at doctor or dentist appointments or in the hospital?

Checklist of common stressors:

Sounds/Noises	Touch	Visual	Smells
People talking	Medical staff touch	New environment	Hospital/dental office smell
Loud noises	Hospital gown	Many people near child	**Tastes**
Beeping alarms	Blood pressure cuff	Entrance to hospital	Liquid medication
Humming monitors	Pulse oximeter	Staff in scrubs, hat, and mask	
Children crying	Tape	Weight scale	
	Identification bracelet	Bed	
	Blood draw/IV insertion	Lights	
	Anesthesia mask		

4. What does your child do when (s)he is anxious or mad and having a meltdown? Are these behaviors mild, moderate, or severe?

Write mild (MI), moderate (MO), or severe (S) next to each behavior listed.

Checklist of common challenging behaviors:

Self-Injurious Behavior	Aggressive and Destructive Behaviors	Stereotyped Behaviors
Self-biting	Hitting others	Rocking, repetitive body movements
Head hitting	Kicking others	Sniffing objects, own body
Body hitting (except for head)	Pushing others	Waving or shaking arms
Self-scratching	Biting others	Manipulating (for example, spinning) objects
Pica (ingesting non-food items)	Grabbing and pulling others	Repetitive hand or finger movements
Inserting objects in nose, ears	Scratching others	Yelling and screaming
Hair pulling	Pinching others	Pacing, jumping, bouncing, running
Teeth grinding	Verbally abusive with others	Rubbing self
	Destroying things	Gazing at hands or objects
	Bullying – being mean or cruel	Bizarre body postures
	Spitting	Clapping hands
		Grimacing

Adapted from *Behavior Problem Inventory-Short (Rojahn, 2011)*

Other:

Covering ears	Closing eyes	Blanket over face and/or body
No interaction with medical staff and others	Crying	Sitting or lying on floor
Removing clothes	Running away	
		None of these

SNAP INTERVENTION SURVEY (CONTINUED)

5. What does your child do when around strangers or his/her doctor?

6. What type of environment is most calming for your child?

7. What does your child like to do for fun or to calm down and relax at home?

8. How does your child communicate with you or let you know when something is wrong?

9. Have you been to Dell Children's surgery department before? Yes No

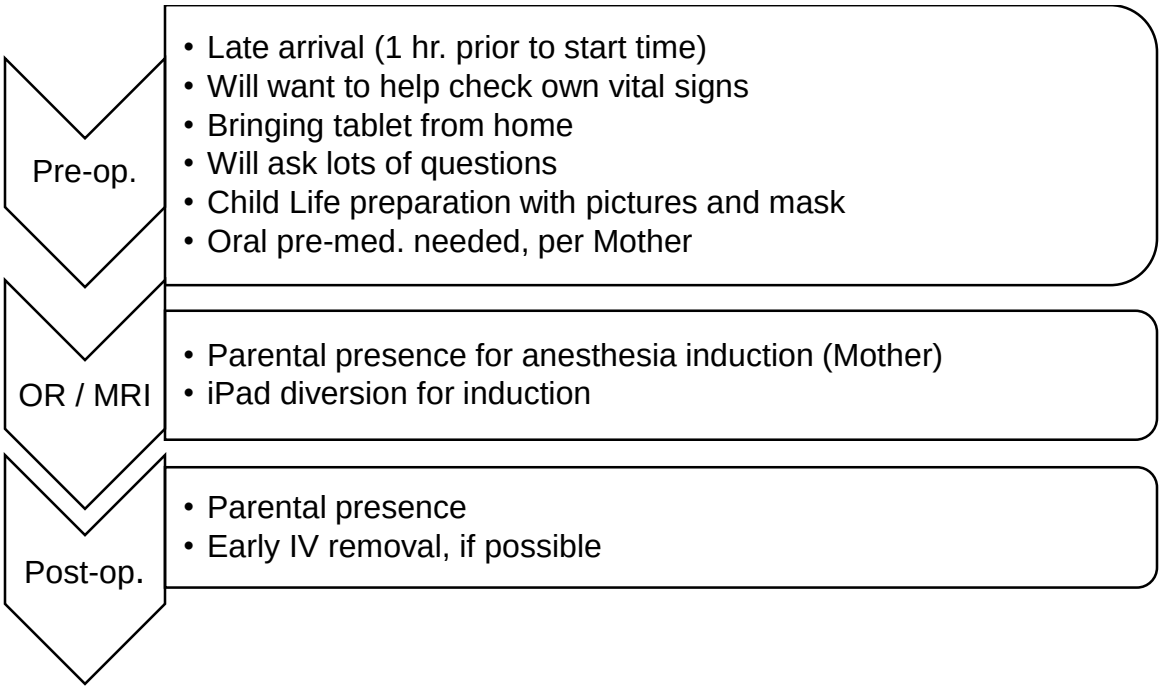
10. What can be done to minimize the stress you and your child will experience when you come to the surgery department?

Appendix E

EXAMPLE OF AN INDIVIDUALIZED COPING PLAN CREATED BY A CHILD LIFE SPECIALIST AND PARENT

Patient:
Gender / Age:
Arrival Time:
Procedure Start Time:
Physician:
Procedure:

PLAN FOR TODAY



STRESSORS / TRIGGERS	COPING SKILLS / LIKES
• **New people** • **Previous traumatic experience in ER** • **Shots**	• **Flash lights** • **Video games, tablet, music** • **Holding stuff: business cards, teddy bears, dogs, gloves**
ESCALATED BEHAVIOR	**COMMUNICATION**
• **Crying** • **Talking** • **Self-harm**	• **Verbal**

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